DEPARTMENT OF LABOR, HEALTH AND HUMAN SERVICES, AND EDUCATION, AND RELATED AGENCIES APPROPRIATIONS FOR FISCAL YEAR 2020

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 serving communities throughout our country. The Corporation for Public Broadcasting (CPB) requests funding of $495 million for fiscal year 2022, $20 million in fiscal year 2020 for the replacement of the public broadcasting interconnection system and other technologies and services, and $30 million for the Department of Education's Ready To Learn program.

Through this uniquely American public-private partnership, 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 overhead. Public media stations in rural, small town and urban communities across the country use these "first-in" Federal dollars to raise, on average, six times that amount from private funding. This indispensable investment provides for the content and community services that address the diverse needs of our viewers and listeners, serving Americans at every stage of their lives.

Parents choose public media content and services to prepare their children for school. They trust public media as a family-friendly, safe environment for learning. This is just one reason why PBS Kids is the number-one educational media brand for supporting children's learning and development. Through the Department of Education's Ready to Learn grant, CPB is helping deliver free, research-based educational content, digital resources for parents and teachers, and safe, online learning experiences for kids. What makes this grant program unique is public television stations' community-based partnerships with Head Start centers, daycare facilities, healthcare centers, faith-based organizations and others to expand the impact of public media's content and resources beyond the broadcast, especially in low-income and underserved communities.

Today's workers are challenged by a rapidly changing economy, requiring different skills for in-demand jobs. Public media is addressing the workforce skills gap through CPB's American Graduate: Getting To Work initiative. Public media stations are working with local businesses, education and workforce-related organizations, connecting potential job seekers with the resources and information they need to pursue jobs and successful careers. CPB funding also makes it possible for public television to operate the largest not-for-profit GED program in the country and for many stations to provide job training and certification courses.

At a time when people are feeling isolated from one another, from our shared culture and from the institutions and organizations that seek to support us, public media matters now more than ever. Through nationwide community conversations, authentic, local storytelling, and effective collaborations and partnerships, the nearly 1,500 locally owned and operated public radio and television stations across the country are playing an important role providing content and engagement that fosters an environment of mutual respect and understanding.

For example, building the foundation for a stronger civil society, CPB is a founding supporter of StoryCorps. StoryCorps, through their One Small Step initiative, is bringing together people of diverse, opposing views for thoughtful conversations in a safe and respectful environment. These conversations are aired on public radio and archived in the Library of Congress. Over the past 5 years, CPB's Veteran's Coming Home initiative has worked to bridge the military-civilian divide and honor those that serve. Through local storytelling events, job fairs, and informational content that leads veterans to assistance, stations are ensuring that the experiences and sacrifices of military members and their families are heard at a time when fewer Americans are serving. This year, a new CPB initiative will provide grants to stations serving rural communities to magnify local stories and explore what "home" means in terms of pride of place, commitment and contribution to one's community, and how our connection to home shapes what it means to be an American.

Because public media stations are locally owned and operated, they are aware early on of local issues that often rise to the level of national impact. Over the past several years, local stations across the country have witnessed the impact of the opioid epidemic. In response, stations in all 50 States have produced thousands of hours of local broadcast and online coverage, hosted hundreds of town halls and other events, and collaborated with experts to direct those affected to the support and resources they need to fight addiction. Nationally, programs such as FRONTLINE, PBS NewsHour and NOVA have covered the opioid issue in depth. In States hardest hit by opioid addiction, CPB-supported journalism collaborations have produced award-winning reporting on the crisis. These stations' daily reporting, which is also published and enhanced online with expanded resources, allows listeners and viewers to engage directly with the support tools they seek.

Public media is owned by the American public. CPB's commitment to diversity and inclusion ensures that Americans of all backgrounds are represented in our content and the creation of our stories. From educational children's content like Molly of Denali, featuring the first Alaska Native lead character in a children's series, that teaches scientific inquiry through adventures in rural, native Alaska; to CPB-supported regional journalism collaborations that elevate local stories and strengthen newsroom and editorial capacity; to documentaries that tell the untold or overlooked history of our diverse society, CPB is living up to its mission to address the needs of unserved and underserved audiences.

Public media stations are committed to serving the needs of their local communities. Their "beyond the broadcast" services are an essential part of that service. Increasingly, State and local public safety officials, schools, education, community and business leaders are seeking to partner with public media. Stations are the backbone of the national Emergency Alert System (EAS), transmitting life-saving warnings from State and local officials about severe weather, evacuation routes and AMBER alerts. Through data-casting capabilities, public television stations work with first responders to deliver instant, secure, encrypted IP data and communications to targeted emergency responders while continuing regular broadcast service.

Today's media environment is marked by disruption and changing demand. Media consumption habits, audience expectations, and media technologies continue to evolve rapidly. Over the past years, CPB has anticipated the changes in the media landscape and responded by investing in shared technology that reduces redundant costs across the system. CPB's investments enable stations to engage more effectively with audiences across the rapidly growing range of digital channels—from websites to apps, new video platforms to smart speakers. Public media has a strong foundation in creating engaging and enriching content which is paired with a commitment to innovation—as content creators, storytellers, and connectors—embracing constantly changing technologies. With additional support, CPB would invest in new technologies and infrastructure that benefit the entire system, so that stations can strategically focus their limited resources on creating additional local content and services. This investment combination will increase our ability to meet audiences where they choose and will enhance their public media experience.

Interconnection Infrastructure: Interconnection is the backbone of the public media system, delivering content every day from public media producers to public television and radio stations in communities throughout the country. Without it, there is no nationwide public media service. Recognizing its importance, Congress has always funded public media's interconnection system since fiscal year 1991 by providing a separate, periodic appropriation for interconnection. CPB appreciates

Congress' support of moving the interconnection infrastructure to an annual, ongoing funding cycle. This allows CPB the flexibility to contract for incremental upgrades as innovations in technology are realized and costs decrease. These efficiencies and technological improvements will advance the system and benefit the American people.

CPB's fiscal year 2022 request of $495 million and fiscal year 2020 requests of $20 million and $30 million for interconnection and Ready To Learn, respectively, provides essential support to stations—particularly those serving rural, minority and other underserved communities—and enables innovation and technological advances. While private donations and existing funding sources help defray costs for the acclaimed programs of public television and radio, the Federal investment is critical to sustaining the operations of public media stations and keeps their services commercial free and available to all Americans free of charge.

We know that Americans value their local public media stations. With your support, CPB will continue to serve as a trusted steward of the Federal appropriation and invest these taxpayer dollars in ways that strengthen the health of our civil society. Mr. Chairman and members of the subcommittee, thank you for allowing me, on behalf of America's public media, to submit this testimony. I appreciate your consideration of our funding request.

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

Prepared Statement of the Railroad Retirement Board

Mr. Chairman and Members of the Committee:

The President's fiscal year 2020 proposed budget for the Railroad Retirement Board (RRB) is $116.225 million. The RRB is requesting $137.216 million. Appropriations for RRB operations are derived from the railroad retirement trust fund system and not the general fund. Appropriations language authorizes the RRB to access available funding from the trust funds to administer comprehensive retirement/survivor and unemployment/sickness insurance benefit programs for railroad workers and their families under the Railroad Retirement (RRA) and Railroad Unemployment Insurance (RUIA) Acts. The RRB also administers certain benefit payments and Medicare coverage for railroad workers under the Social Security Act.

Last year, the RRB paid $13.1 billion, net of recoveries and offsetting collections, in retirement/survivor benefits to about 540,000 beneficiaries, including $1.8 billion in benefits paid to about 124,000 beneficiaries on behalf of the Social Security Administration. Further, the RRB paid $100.2 million in unemployment-sickness benefits net of recoveries and offsetting collections to about 25,000 railroad workers.

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

PRESIDENT'S PROPOSED FUNDING FOR AGENCY ADMINISTRATION

The RRB's risk of mission failure is increasing substantially due to insufficient staffing levels and antiquated IT systems. The President's proposed budget would provide $116.225 million for agency operations, to include IT initiatives, and support 744 full-time equivalents (FTEs). The RRB requests an additional $20.991 million above the President's proposed $116.225 million for a total of $137.216 million to be derived from the railroad retirement trust fund system (not the general fund). Of the additional $20.991 million, $11.854 supports increased staffing for core programmatic activities and $9.137 million for continued implementation of the RRB's IT modernization program. The remainder of this testimony will focus on these critical priorities with a few additional topics in conclusion.

CRITICAL PRIORITY: AGENCY STAFFING

For fiscal year 2020, the President's proposed amount of $116.225 million would support 744 FTEs, which is 106 less than the minimum, 850 FTEs, needed to sustain mission critical operations. From 1993 through 2018, the RRB has reduced staffing levels by more than half and by fiscal year 2020, 34 percent of our current workforce will be eligible to retire.

Operating with less than 850 employees has and will continue to significantly decrease available customer service and office hours in the RRB's 53 field offices, resulting in unpredictable temporary office closures. As a result, railroad beneficiaries will continue to encounter significant delays in receiving assistance for benefits and counseling. Further, the growing backlog in retirement, survivor, and disability casework will continue to increase because of insufficient staffing. This will have a direct impact on payment of benefits. Therefore, for fiscal year 2020, the RRB requests an additional $20.991 million, $11.854 million above the President's proposed amount of $116.225 million. Of the $20.991 million, $11.854 million would fund increased staffing levels to the 850 FTEs that are necessary until modernized technology can sustain organization performance at lower staffing levels in the future.

CRITICAL PRIORITY: INFORMATION TECHNOLOGY (IT)

We are grateful for the support and $20 million provided thus far for the RRB's IT modernization program; $10 million provided under Public Law 115–245, Department of Defense, and Labor, Health and Human Services, and Education Appropriations Act, 2019 and $10 million provided under Public Law 115–141, Consolidated Appropriations Act, 2018. As a result of these appropriations, the RRB has initiated an aggressive IT modernization program to transition the agency from its antiquated IT systems that do not meet current Federal Information Security Modernization Act (FISMA) mandates to modern benefit calculation and payment processing capabilities made possible by leveraging best value shared services, cloud services, and self-service digital solutions for our customers. These funds have allowed the RRB to contract for re-platforming services that will eliminate the risk of aging mainframe hardware by transitioning the agency to a cloud based solution. Additionally, RRB has made progress on the Legacy Systems Modernization Services and the Financial Management Integrated System Upgrade projects. RRB continues to work with GSA on contracts necessary to implement the mandated Enterprise Infrastructure Solutions. Additional details on the progress of IT modernization are located in the quarterly progress reports submitted to your office.

For fiscal year 2020, the RRB requests an additional $20.991 million above the President's proposed amount of $116.225 million. Of the $20.991 million in additional funds requested, $9.137 million would be designated for IT initiatives to allow continued progress on the RRB's ongoing critical modernization efforts. The additional investment will also facilitate compliance with cybersecurity and privacy mandates; improve and expand our data analytical capabilities to reduce the risk of fraud through stronger program integrity measures; and ultimately create a more effective and efficient organization capable of achieving the mission with fewer people.

LEGISLATIVE PROPOSALS

The RRB's budget request includes four legislative proposals. The first proposal seeks to eliminate the competitive civil service requirement in Section 7(b) (9) of the Railroad Retirement Act, so that the RRB could use the various hiring authorities available to other Federal agencies. The second would allow the RRB to utilize student and recent graduate hiring authorities available to other Federal agencies. The third would amend the RRA and the RUIA to include a felony charge for individuals committing fraud against the agency. The last would amend the Social Security Act to provide access for the RRB to the National Directory of New Hires (NDNH) that would support the RRB's program integrity efforts to prevent improper payments.

FINANCIAL STATUS OF THE TRUST FUNDS

Railroad Retirement Accounts.—The RRB continues to coordinate its activities with the National Railroad Retirement Investment Trust (Trust), which was established by the Railroad Retirement and Survivors' Improvement Act of 2001 (RRSIA) to manage and invest railroad retirement assets for the payment of benefits. Pursuant to the RRSIA, the RRB 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, 2018, was approximately $26.6 billion, an increase of almost $100 million from the previous year. Through February 1, 2019, the Trust had transferred approximately $23.684 billion to the RRB for payment of railroad retirement benefits.

The RRB's latest report required by the Railroad Retirement Act of 1974 and Railroad Retirement Solvency Act of 1983 was released in June 2018. The overall conclusion was, barring a sudden, unanticipated, large drop in railroad employment or substantial investment losses, the railroad retirement system will experience no cash flow problems during the next 29 years. The report recommended no change in the rate of tax imposed on employers and employees. The tax adjustment mechanism would 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 29 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 2018. The report indicated that even as maximum daily benefit rates are projected to rise approximately 51 percent (from $72 to $109) from 2017 to 2028, 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 Erhard R. Chorlé, Chairman, John Bragg, Labor Member, and Thomas R. Jayne, Management Member, Railroad Retirement Board.]

NONDEPARTMENTAL WITNESSES

PREPARED STATEMENT OF THE ACADEMY FOR RADIOLOGY & BIOMEDICAL IMAGING RESEARCH

Mr. Chairman and Members of the Subcommittee, my name is Dr. Mitchell Schnall, and I am privileged to serve as Vice President of the Academy for Radiology & Biomedical Imaging Research ("the Academy"). I am testifying today to thank you for your dedicated support of medical imaging, and to request your support for raising the funding for the National Institutes of Health to no less than $41.6 billion and increasing the funding for the National Institute of Biomedical Imaging and Bioengineering (NIBIB) by at least $25 million.

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

On behalf of the Academy, I would like to begin by thanking you for your generous support for the National Institutes of Health in the fiscal year 2019 LHHS appropriations bill. This increase in funding contributes to the important work of improving our biomedical research infrastructure while also ensuring that the United States remains the leader in medical innovation and technology.

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

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

—Please fund the NIH at no less than $41.6 billion for fiscal year 2020.

—Please increase NIBIB funding by no less than $25 million for fiscal year 2020.

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

For nearly every patient—nearly every constituent—who receives a cancer diagnosis, suffers a head injury, or experiences any of thousands of other medical issues, or who cares for family members experiencing such difficulties, the health benefits of imaging and bioengineering research are profoundly felt. Few medical conditions do not already benefit from any of the wide range of clinical imaging modalities, from x-rays to MRI, CT, PET, fluoroscopy, angiography, and ultrasound. Furthermore, scientific discoveries and technological innovations are rapidly expanding the power of biomedical imaging and bioengineering to improve medical care. In the area of cancer, for example, emerging techniques for molecular imaging will play a key role in realizing the dream of molecularly-targeted treatment, as, unlike biopsies, they can give a non-invasive picture of the biological heterogeneity of cancer within and across all tumors in a patient. Progress is also accelerating in the use of computer tools, including artificial intelligence and machine learning, to analyze both anatomical and molecular images and identify mathematically defined features, not perceptible to the human eye, which can predict the presence of cancer, its genetic profile, and how well it is likely to respond to specific treatments. Furthermore, the use of increasingly advanced imaging tools to guide medical interventions is allowing more precise, less invasive procedures, in some cases with immediate assessment of efficacy to enable necessary adjustments before a procedure is concluded.

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

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

To help achieve these objectives, the Academy is working closely with allies across academia, government, and industry to identify and pursue specific, effective steps to implement the building of the Diagnostic Cockpit (DxCP) of the future—an entity that will integrate advanced imaging and other diagnostic and bioengineering tools to improve diagnosis and thereby further enhance the precision and efficiency of healthcare delivery. The Academy has convened leaders in biomedical imaging and bioengineering from academia, government, and industry to work collaboratively on this project. The DxCP is a vision for today and for the future that will be made possible by a consistent and robust investment in biomedical imaging research. The sooner we invest, the sooner your constituents benefit.

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

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

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

PREPARED STATEMENT OF ACADEMYHEALTH

AcademyHealth is pleased to offer this testimony regarding funding for Federal agencies that support health services research and health data, including the Agency for Healthcare Research and Quality (AHRQ). AcademyHealth works to improve health and the performance of the health system by supporting the production and use of evidence to inform policy and practice. We represent the interests of more than 4,000 health services researchers, policy analysts, and practitioners that produce and use health services research to improve our Nation's health and the performance of the healthcare and public health systems. For fiscal year 2020, AcademyHealth recommends a funding level of $460 million in budget authority for AHRQ, consistent with the agency's fiscal year 2010 appropriated budget, adjusted for inflation.

Health services research is our Nation's R&D enterprise for health improvement. Just as medical research discovers cures for disease, health services research discovers cures for the health system (see Figure 1). This research diagnoses problems in healthcare and public health delivery and identifies solutions to improve outcomes for more people, at greater value. And while biomedical and clinical research discoveries can take years and even decades to reach patients, discoveries from health services research can be used now by patients, healthcare providers, public health professionals, hospitals, employers, and public and private payers to improve care today.

Figure 1: The Health Research Continuum

These components of the health research continuum work in concert, and each plays an essential role—any one type of research on its own cannot effectively or appreciably improve health. Take heart disease as one example . . .

Basic research discovered the contributions of elevated blood pressure, elevated cholesterol, and tobacco use to heart disease.	**Clinical research** determined which treatments were safe and effective to treat hypertension, hypercholesterolemia, tobacco addiction, and to prevent and treat heart disease, in general.	**Population-based research** identified strategies to reduce the risks of heart disease in communities through non-medical interventions, such as reduction of trans fats in food and tobacco control measures to reduce smoking.	**Health services** research determined how to best deploy these discoveries to achieve the best health outcomes. This research helped identify who had the least access, what barriers existed, and how to address them. This research also led to the development of quality measures that are now used to report on the quality of cardiac care.

Source: AHRQ: 15 Years of Transforming Care and Improving Health, AcademyHealth, Jan. 2014. Available at: http://academyhealth.org/files/AHRQReport2014.pdf.

Put plainly, health services research helps Americans get their money's worth when it comes to healthcare. We need more of it, not less. Despite the positive impact health services research has had on the U.S. healthcare system, and the potential for future improvements in quality and value, the United States spent less than one cent of every healthcare dollar on health services research.

As the largest purchaser of healthcare—more than $1 trillion per year and rising—the Federal Government has an enormous stake in spending each health dollar wisely. Patients deserve healthcare that works for them, and taxpayers deserve smart spending. Indeed, in poll after poll, healthcare costs are consistently top of mind for Americans. As the lead Federal agency for health services research, AHRQ is uniquely positioned to generate evidence to ensure Americans get the best care at the best value.

The vast majority of federally funded research focuses on individual diseases, organ systems, cellular, or chemical processes. AHRQ is the only Federal agency that funds research at universities and other research institutions throughout the Nation on the primary care and health systems serving real patients, those who have complex comorbidities, and the interactions and intersections of healthcare providers. AHRQ also provides the data needed to monitor the healthcare landscape nationally and within States, speeds new medical findings to healthcare providers and patients, and provides them with the tools and training they need to use those findings every day to improve the quality and safety of patient care.

An example of AHRQ's successful work includes efforts to reduce hospital acquired conditions. New, preliminary data from AHRQ finds that by implementing transformational, AHRQ-funded research, the Centers for Medicare and Medicaid Services (CMS) has reduced hospital-acquired conditions, and prevented an estimated 20,500 hospital deaths and saved $7.7 billion in healthcare costs from 2014 to 2017.

In addition, AHRQ funded research grants are finding ways to ensure rural primary care practices are equipped to respond to the opioid crisis. An explosion in the incidence of opioid addiction and overdoses, particularly in rural areas of the country, has elevated this issue to crisis-level in the United States. Primary care practices are often the first line of defense against this and other substance use disorders.

AcademyHealth joins the Friends of AHRQ—an alliance of 150 health professional, research, consumer, and employer organizations that support the agency—in recommending $460 million in budget authority for AHRQ in fiscal year 2020, which is consistent with the fiscal year 2010 level adjusted for inflation. This funding level would allow AHRQ to rebuild portfolios terminated as a result of years of past cuts and expand its research and training portfolio to address our Nation's pressing and evolving healthcare challenges. Additionally, with a quarter of the agency's program level budget supported by the Patient-Centered Outcomes Research Institute and its associated trust fund, a strong investment in the AHRQ appropriation will be essential to sustain the agency's core activities as PCORI undergoes reauthorization this year. AcademyHealth has joined other groups to support the reauthorization of PCORI, but if those efforts fail, the loss of the trust fund would result in a 25 percent cut to AHRQ's budget that would cripple the agency's ability to achieve its important mission.

AcademyHealth is mindful that AHRQ and other domestic programs face a scheduled, statutory $55 billion cut—11 percent across the board—if lawmakers are unable to enact legislation to raise the discretionary spending caps in fiscal year 2020. Our proposed funding recommendation for AHRQ can only be achieved if such a bipartisan budget deal is reached. We have joined nearly 1,000 organizations across the research, public health, education, housing, natural resources, and other sectors in calling upon Congress and the White House to raise the caps before the end of the fiscal year, and we have endorsed the Investing in the People Act (HR 2021).

The accomplishments of the field of health services research would not be possible without the leadership and support of this subcommittee, and AcademyHealth recognizes the importance of investing Federal funds strategically. We strongly believe that AHRQ more than earns a place among your appropriations priorities, and urge you to provide the agency $460 million in budget authority in fiscal year 2020. Doing so would signal your continued commitment not just to produce discoveries for the future, but to produce science that translates medical progress into better care for patients today.

Thank you for considering our recommendation. For more information, including a copy of our report on AHRQ's contributions to improved health and healthcare over the years, please contact Dr. Lisa Simpson, President and CEO of AcademyHealth, at lisa.simpson@academyhealth.org.

[This statement was submitted by Dr. Lisa Simpson, President & CEO, AcademyHealth.]

PREPARED STATEMENT OF THE ACCELERATE CURE/TREATMENTS FOR ALZHEIMER'S DISEASE

Dear Chairmen Shelby and Cole and Ranking Members Leahy and Murray,

Accelerate Cure/Treatments for Alzheimer's Disease (ACT–AD) is comprised of more than 50 national organizations representing patients, caregivers, researchers, health professionals, and other health advocates. Our mission is to support efforts to expedite the development, review, and approval of transformational therapies for Alzheimer's disease. We appreciate the opportunity to submit testimony on the fiscal year 2020 Labor, Health and Human Services, Education, and Related Agencies appropriations process.

Alzheimer's disease is devastating both emotionally and financially for the estimated 5.8 million Americans living with the disease and their families. We would like to thank you for your strong leadership and support of biomedical research at the National Institutes of Health (NIH) and the National Institute on Aging (NIA) in fiscal year 2019. The research funded by your respective committee's has helped us understand much more about this complicated disease.

As you prepare the fiscal year 2020 appropriations legislation, we ask for sufficient Federal resources be dedicated to sustaining and enhancing biomedical research at the NIA, and across the NIH. 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 ACT–AD supports the AD Hoc Group for Medical Research's recommendation to appropriate at least $41.6 billion in fiscal year 2020 for the NIH, including funds provided through the 21st Century Cures Act for targeted initiatives.

In addition, we request targeted funding increases for aging and Alzheimer's disease and related dementia (ADRD) research to sustain the promising work of the NIH in these domains. Specifically, ACT–AD requests a $500 million increase in the fiscal year 2020 NIH budget to support aging research, including biomedical, behavioral, and social science research efforts. Additionally, we request a minimum increase of $350 million in funding for ADRD research. These increases are necessary to ensure the NIH and NIA have the resources they need to address dementia and many other age-related chronic diseases.

Please consider the ACT–AD coalition a resource to you and your staff. If you have questions or more additional information, please contact Ryne Carney at rcarney@agingresearch.org. Additionally, we are located at 1700 K Street, NW, Suite 740, Washington, DC 20006.

Sincerely.

[This statement was submitted by Missy Jenkins, Executive Director, Accelerate Cure/Treatments for Alzheimer's Disease.]

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) through a recommendation of at least $41.6 billion for NIH in fiscal year 2020.

As a result of the strong, bipartisan vision of Senate and House Labor-HHS-Education Appropriations Subcommittees over the last 4 years, Congress has helped the agency regain some of the ground lost after years of effectively flat budgets. This renewed investment in NIH has advanced discovery toward promising therapies and diagnostics, reenergized existing and aspiring scientists nationwide, and restored hope for patients and their families.

For fiscal year 2020, more than 315 stakeholder organizations supported the Ad Hoc Group recommendation of at least $41.6 billion for the NIH, a $2.5 billion increase over the NIH's program level funding in fiscal year 2019. This funding level would allow for meaningful growth above inflation in the base budget that would expand NIH's capacity to support promising science in all disciplines in addition to special initiatives. It also would ensure that funding from the Innovation Account established in the 21st Century Cures Act would supplement the agency's base budget, as intended, through dedicated funding for specific programs. We are appreciative that the fiscal year 2020 spending bill approved by the House Appropriations Committee would continue the sustained funding momentum of the last 4 years through an increase in NIH's base budget, and meaningfully bolster funding for all Institutes and Centers across the agency. We believe that supplementing the targeted funding with substantial, across the board increases will yield the greatest return on investment.

In addition, we recognize that the impractical budget caps imposed by the Budget Control Act of 2011 undermine necessary investment in the full range of critical Federal priorities. The Ad Hoc Group is among the nearly 850 organizations and 15 research-focused coalitions urging a bipartisan budget deal to increase the caps for nondefense discretionary spending and joins the Coalition for Health Funding, Coalition on Human Needs, Committee for Education Funding, and Campaign to Invest in America's Workforce in advocating a significant increase in the subcommittee's 302(b) allocation in fiscal year 2020.

We believe that science and innovation are essential if we are to continue to meet current and emerging health challenges, improve our Nation's physical and fiscal health, and sustain our leadership in medical research. As the Subcommittee has recognized, to remain a global leader in accelerating the development of life-changing cures, pioneering treatments, and innovative prevention strategies, it is essential that Congress sustain robust increases in the NIH budget.

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

NIH has supported biomedical research to enhance health, lengthen life, 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.

- —Breakthroughs in the treatment of depression came in early 2019 with FDA approval of two new drugs—one for treatment-resistant depression and the first ever treatment for postpartum depression. These approvals follow nearly three decades of research funded by the NIH to identify novel mechanisms of drug action.
- —The NIH has supported research on sickle cell disease (SCD) since 1948, and the disease currently affects about 100,000 Americans. Today, an ongoing multicenter clinical trial is using gene therapy to replace the defective gene that causes SCD, beta globin, in patient's blood cells and effectively curing them of disease.
- —In 2007, induced pluripotent stem cells (iPSCs) were discovered when adult cells were re-engineered into early non-differentiated versions of themselves. Today, researchers have used iPSCs to successfully treat a major cause of blindness—age-related macular degeneration—in animal models and are awaiting FDA approval to begin the first iPSC clinical trial in the U.S.

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

—The widespread use of the measles vaccine since its development in the 1960s led to a 99.9 percent decrease in annual cases of the disease compared to prevaccine levels, officially eliminating the disease in the U.S. in 2000. Every $1 spent on routine childhood vaccinations, including against measles, is estimated to save $5 in direct costs, and $11 in broader costs to society.

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

—NIH funding supported research that contributed to all of the 210 new drugs approved by the FDA between 2010 and 2016.

—The death rate for all cancers combined has been declining since the early 1990s for adults and since the 1970s for children. Overall cancer death rates have dropped by nearly 27 percent with more than 2.6 million deaths avoided in total between 1991 and 2016. 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 68 percent from 1969 to 2015, 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.

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

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

One long-lasting potential impact of investments in NIH is on the next generation of scientists. The Federal commitment to NIH sends a strong signal to these aspiring researchers about the stability of a long-term career in medical research. Of particular interest is maintaining a cadre of clinician-scientists to facilitate translation of basic research to human medicine. Even with the recent investment in NIH, nearly 4 of every 5 research ideas that are proposed to NIH every year cannot be funded. Additional funding is needed if we are to strengthen our Nation's research capacity, ensure a medical research workforce that reflects the racial and gender diversity of our citizenry, and inspire a passion for science in current and future generations of researchers.

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

NIH: An Answer to Challenging Times. Research supported by NIH drives local and national economic activity, creating skilled, high-paying jobs and fostering new products and industries, and catalyzes increases in private sector investment. A $1 increase in public basic research stimulates an additional $8.38 investment from the private sector after 8 years. A $1 increase in public clinical research stimulates an additional $2.35 in private sector investments after 3 years. According to a United for Medical Research report, in fiscal year 2018, NIH-funded research supported more than 433,000 jobs across the U.S. and generated nearly $74 billion in new economic activity.

The Ad Hoc Group's members recognize the tremendous challenges facing our Nation and acknowledge the difficult decisions that must be made to restore our country's fiscal health. Strengthening our commitment to medical research, through robust funding of the NIH, is a critical element in ensuring the health and well-being of the American people and our economy. Therefore, for fiscal year 2020, the Ad Hoc

Group for Medical Research recommends that NIH receive at least a $41.6 billion to continue the momentum in our Nation's investment in medical research.

PREPARED STATEMENT OF ADVANCE CTE

Advance CTE is the longest-standing national non-profit that represents State Directors and State leaders responsible for secondary, postsecondary and adult Career Technical Education (CTE) across all 50 States and U.S. territories. Advance CTE's mission is to support visionary State leadership, cultivate best practices, and speak with a collective voice to advance high-quality CTE policies, programs and pathways that ensure career success for each learner. On behalf of our members, Advance CTE is pleased to submit written testimony about the Federal investment in CTE State Grants (authorized under Title I of the Strengthening Career and Technical Education for the 21st Century Act (Perkins V)) for fiscal year 2020 (fiscal year 2020) that is administered through the U.S. Department of Education. Building on the increases in fiscal year 2018 and fiscal year 2019, Congress should double the Federal investment in CTE State Grants from the fiscal year 2018 level by fiscal year 2024. In order to fully support the implementation of Perkins V and the 12.1 million learners it serves across the Nation, in fiscal year 2020, Congress should make a strong down payment toward this goal by providing $1.52 billion.[1]

CTE programs are delivering real results. Across the country, CTE programs are preparing learners for promising career paths and giving employers and our economy a competitive edge.[2] CTE programs provide unique opportunities for learners to engage with employers and participate in internships, apprenticeships and other meaningful on-the-job experiences. In addition, these programs produce strong outcomes for the learners they serve. For example, students involved in CTE are far less likely to drop out of high school than other students, a difference estimated to save the economy $168 billion each year.[3] The results for adult learners are also impressive: 86 percent of adults concentrating in CTE either continued their education or were employed within 6 months of completing their program.[4] In fact, 90 percent of Americans agree that apprenticeships and skills training programs prepare students for a good standard of living.[5]

CTE programs can serve even more learners and employers—but only if they receive more resources. Nearly 60 percent of companies report having difficulty filling job openings because of a lack of qualified applicants, which can cost a company more than $800,000 each year in lost productivity and recruitment.[6] In addition, there are now more open jobs in the U.S. than there are unemployed Americans. It's clear that the 21st century economy is creating skilled careers faster than our schools, colleges, and CTE programs can prepare learners for these opportunities. And there's widespread support for CTE: 94 percent of parents approve of expanding access to CTE.[7] However, a survey of school districts offering CTE found that the top barrier to offering CTE in high school was a lack of funding or the high cost of the programs.[8] As the chart below demonstrates, between fiscal year 2004 and fiscal year 2017, funding for CTE State Grants declined by over $77 million dollars, the equivalent of $427 million inflation-adjusted dollars (i.e., 28 percent in inflation-adjusted dollars).

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[1] Refers to Program Year 2016–17. Source: https://perkins.ed.gov/pims/DataExplorer/CTEParticipant.

[2] https://careertech.org/excellence-action-award.

[3] https://files.eric.ed.gov/fulltext/EJ943149.pdf.

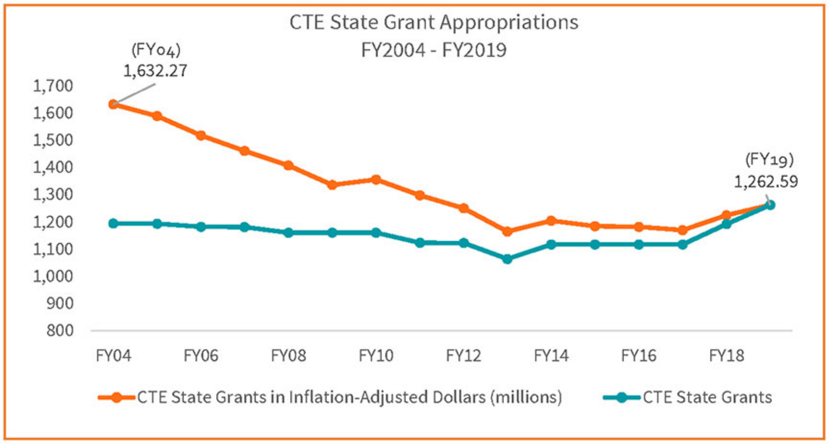
[4] Includes only States that report data on adult CTE learners to the U.S. Department of Education. Retrieved from https://perkins.ed.gov/pims/DataExplorer/Performance.

[5] https://www.newamerica.org/education-policy/reports/varying-degrees-2018/executive-summary/.

[6] http://press.careerbuilder.com/2017-04-13-The-Skills-Gap-is-Costing-Companies-Nearly-1-Million-Annually-According-to-New-CareerBuilder-Survey.

[7] https://www.aft.org/sites/default/files/parentpoll2017__memo.pdf.

[8] https://nces.ed.gov/pubs2018/2018028.pdf.



Taking a longer view, before fiscal year 2018, the investment in CTE State Grants had been relatively flat since 1991, and without being tied to inflation, the program's buying power had fallen by approximately $933 million in inflation-adjusted dollars since 1991—a 45 percent reduction over a quarter century.[9]

Congress recognized the need to begin to reverse this trend and in fiscal year 2018, provided an additional $75 million for CTE State Grants, bringing the total investment to nearly $1.2 billion. In July 2018, the Carl D. Perkins Career and Technical Education Act of 2006 was reauthorized as the Strengthening Career and Technical Education for the 21st Century Act (Perkins V) and in fiscal year 19, Congress invested an additional $70 million in CTE State Grants to nearly $1.3 billion. These were very welcome steps in the right direction and reflects Congress' understanding of the critical role CTE plays in helping our Nation's learners and employers close the skills gap. Congress should build on the momentum in fiscal year 2018 and fiscal year 2019, and continue to strengthen the investment in CTE State Grants in fiscal year 2020. And, Americans agree: 93 percent of voters support increasing the investment in skills training, and more than half of voters strongly support this idea.[10]

Expanding funding for CTE programs will create a brighter future for our community—leading to more career options for learners, better results for employers, and increased growth for our economy. Learners enrolled in CTE are increasingly high performers, with higher than average graduation rates and impressive postsecondary enrollment rates. The graduation rate for students who take a concentration of CTE courses is about 94 percent, approximately 10 percentage points higher than the national average.[11] For example, in Missouri, the high school graduation rate for students who took a concentration of CTE courses in the 2016–2017 program year (the most recent year for which data are available), was over 96 percent and for Tennessee, it was over 97 percent.[12] Even achieving a 90 percent graduation rate nationwide would have a significant impact—it's estimated that it would result in a $5.7 billion increase in economic growth and $664 million in additional Federal, State and local taxes (calculated for the class of 2015).[13] Not only are students who concentrate in CTE more likely to graduate from high school, they find success afterward as well. In Alabama, nearly 94 percent of secondary students who concentrated in a CTE program were enrolled in college, enlisted in the military or working within 6 months of graduation.[14] In Vermont, 88 percent of postsecondary CTE graduates placed into careers, military service or apprenticeship programs

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

[10] https://www.nationalskillscoalition.org/news/press-releases/body/Poll-Finds-Overwhelming-Support-for-More-Funding-for-Skills-Training.pdf.

[11] https://perkins.ed.gov/pims/DataExplorer/Performance and https://nces.ed.gov/ccd/tables/ACGR__RE__and__characteristics__2015-16.asp.

[12] https://perkins.ed.gov/pims/DataExplorer/Performance.

[13] http://graduationeffect.org/US-GradEffect-Infographic.pdf.

[14] https://perkins.ed.gov/pims/DataExplorer/Performance.

within 6 months.[15] It is also important to highlight that CTE learners are not the only ones accruing the many benefits of CTE—taxpayers are also seeing a high return on investment (ROI). For example, in Washington, secondary CTE sees a ROI of $7 for every one dollar of investment.[16] If we are serious about providing learners with the real-world skills, hands-on opportunities and real options for college and rewarding careers that come with CTE and making progress toward closing the skills gap, then there is no better time than now to invest $1.52 billion in CTE State Grants, which would be a strong down payment on doubling the Federal investment in CTE State Grants by fiscal year 2024.

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

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

PREPARED STATEMENT OF AIDS ALLIANCE

Dear Chairman Blunt and Members of the Subcommittee:

AIDS Alliance for Women, Infants, Children, Youth & Families (AIDS Alliance) was founded in 1994 to help respond to the unique concerns of HIV-positive and atrisk 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 2020 Labor, Health and Human Services, Education, and Related Agencies appropriations measure and endorse maintaining separate funding and support for Part D of the Ryan White Program.

RYAN WHITE PART D FUNDING REQUEST

Sufficient funding of Ryan White Part D, the program funded solely to provide family-centered primary medical care and support services for women, infants, children, and youth with HIV/AIDS has successfully identified, linked, and retained these vulnerable populations in much needed care and treatment, resulting in optimum health outcomes. We thank the Subcommittee for its continuous support of the Ryan White Program and respectfully request that the Subcommittee maintain its commitment to the Ryan White Part D and increase Ryan White Part D funding by $9.9 million in fiscal year 2020.

RYAN WHITE PART D BACKGROUND AND HISTORY

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

In fiscal year 2018, Ryan White Part D provided funding to 115 community-based organizations, including academic medical centers and hospitals, federally qualified

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[15] https://perkins.ed.gov/pims/DataExplorer/Performance.

[16] http://www.wtb.wa.gov/CTE2018Dashboard.asp.

health centers, and health departments in 39 States and Puerto Rico with $70.3 million to provide comprehensive outpatient ambulatory family-centered primary and specialty medical care and support services for women, infants, children and youth with HIV. These grant recipients also provide case management services (medical and non-medical); referrals for inpatient hospital services; treatment for substance use, and mental health services. Part D recipients also receive assistance from other parts of the Ryan White Program that help support HIV testing and linkage to care services; provide access to medication; additional medical care, such as dental services; and key support services, such as case management and transportation, which all are essential components of the highly effective Ryan White HIV care model. This model has continuously provided comprehensive quality healthcare delivery systems that have been responsive to women, infants, children, youth and families for three decades.

A RESPONSE TO WOMEN, INFANTS, CHILDREN, AND YOUTH

Ryan White Part D programs have been extremely effective in bringing our most vulnerable populations into care and developing medical care and support services especially designed to reach women, infants, children, and youth. The groundbreaking results of the AIDS Clinical Trial Group study 076 that proved the efficacy of AZT in preventing mother-to-child transmission of HIV was significant for Ryan White Part D programs as these programs played a leading role in reducing mother-to-child transmission of HIV-from as many as 2000 babies born HIV-positive in 1990 to roughly 181 cases in 2012. As appropriate funding is critical to maintain and improve upon this success, AIDS Alliance was pleased that the President's fiscal year 2019 budget focused on accelerating the elimination of perinatal HIV infection in the United States. Appropriate funding is critical to maintain and improve upon this success, as an estimate for 2006 suggested that approximately 8,500 HIV-positive women that need counseling services and support to prevent pediatric HIV infections were giving birth every year in the United States. The most recent available data reports that 11,355 infants (including HIV exposed infants) and children were served by Ryan White Part D in 2010. According to the CDC, youth aged 13–24 made up 21 percent of all new HIV diagnoses in the country in 2016, with eighty-one percent of those new diagnosis among young gay and bisexual males. Eighty-seven percent of new HIV cases among women of the same age group were attributed to heterosexual contact. Ryan White Part D programs are the entry point into medical care for many of these HIV- positive youth as this is the age group least likely to have access to quality healthcare. Though HIV diagnoses among women have declined in recent years, more than 7,000 women received an HIV diagnosis in 2017. According to the Health Resources and Services Administration, approximately 27.1 percent of women received medical care from Ryan White Programs in 2017. Part D provides medical and supportive services to a large number of women over 50 who are HIV survivors which is a testament to the high standard of care provided to Ryan White Part D programs. Support and care through the Ryan White Part D program was and continues to be funding of last resort for the most vulnerable women and children, who often have fallen through the cracks of other public health safety nets. The continuation of the Ryan White Program, in particular Ryan White Part D 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 support services provided by Part D are uniquely tailored to address the needs of women, including HIV positive pregnant women, HIV exposed infants, children and youth living with HIV/AIDS and are central components of a highly effective model of care designed to achieve optimal health outcomes. The family-centered primary medical and specialty care along with 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 remain a critical component of the Ryan White Program as their vast networks of service providers are fully engaged in addressing and meeting the critical healthcare needs of women, infants, children and youth with HIV/AIDS.

CONCLUSION

While we recognize the considerable fiscal constraints Congress faces in allocating limited Federal dollars, the requested increase of $9.9 million in fiscal year 2020 will enable Ryan White Part D programs, (often referred to as the lifeline for women, infants, children, and youth), to continue to deliver life-saving HIV/AIDS care and treatment for women, infants, children and youth with HIV and to ensure that these populations are fully engaged and retained in care. Without the Ryan White Part D program, many of these medically-underserved populations with HIV would not receive the vital medical care and support services they need. We thank the Subcommittee for its work in ensuring that women, infants, children, and youth, living with HIV receive the much needed care and treatment services necessary to sustain their lives.

[This statement was submitted by Dr. Ivy Turnbull, Deputy Executive Director, AIDS Alliance.]

PREPARED STATEMENT OF THE AIDS INSTITUTE

Dear Chairman Blunt and Members of the Subcommittee:

The AIDS Institute, a national public policy, research, advocacy, and education organization, is pleased to offer testimony in support of domestic HIV and hepatitis programs in the fiscal year 2020 Labor, Health and Human Services, Education, and Related Agencies appropriation measure. We thank you for your continued support and respectfully request $291 million for the Administration's Ending the HIV Epidemic Plan, to be distributed among several HHS programs. We further request $1.012 billion for the CDC's HIV Prevention Programs; $2.557 billion for the HRSA's Ryan White HIV/AIDS Program; $105 million for the Minority HIV/AIDS Fund; $160 million for SAMHSA's Minority AIDS Initiative Program; $3.502 billion for HIV/AIDS Research at the NIH; $58 million for opioid related infectious disease programs at the CDC and $134 million for CDC's Viral Hepatitis Programs. (Note: as detailed below some of these requests encompass funding for the Ending the HIV Epidemic initiative.)

HIV IN THE UNITED STATES

Over 1.2 million people in the U.S. are living with HIV, only about half of whom are virally suppressed, and there are an estimated 38,500 new infections each year. While we have made great progress since the height of the epidemic, over the past 5 years the number of new HIV diagnoses have remained stagnant at around 40,000 per year. HIV continues to disproportionately impact certain populations, including gay and bisexual men, the African American community, people living in the South, people who inject drugs, and the transgender community. The AIDS Institute believes that the United States has the treatment and prevention tools necessary to end the epidemic, but doing so will require increased Federal investments in the public health infrastructure that serves people living with and at risk of HIV. The vast majority of the discretionary programs supporting domestic HIV efforts are funded through this Subcommittee.

ENDING THE HIV EPIDEMIC: A PLAN FOR AMERICA

This year we have a unique opportunity to begin to make significant progress towards the goal of ending the HIV epidemic because of the Administration's new initiative entitled "Ending the HIV Epidemic: A Plan for America." This plan sets a bold but achievable goal of reducing HIV infections by 75 percent in the next 5 years and 90 percent by 2030. The plan builds on the existing infrastructure serving people with and at risk of HIV with innovated and intensified testing, treatment and prevention programs. The AIDS Institute strongly supports this plan and urges your Subcommittee to adopt the $291 million in first year funding proposed in the President's Budget.

Of this funding, $140 million would be for the CDC Division of HIV/AIDS Prevention to do targeted testing, connection to treatment, and robust surveillance; $70 million would be for the Ryan White HIV/AIDS Program to increase access to high-quality HIV care and treatment; $50 million would be for HRSA's Community Health Center program to provide prevention services, emphasizing PrEP; $6 million would be for NIH's Centers for AIDS Research to provide best practices to guide the plan; and finally, $25 million would be for the Indian Health Service to provide HIV prevention, treatment, education, and hepatitis C (HCV) elimination in Indian Country. This coordinated, targeted and robust plan will be community driven—incorporating voices of those who could benefit most from prevention and treatment tools. The AIDS Institute urges your Subcommittee to fund this request and ensure that these are new funds are not at the cost of other programs.

The AIDS Institute has also submitted suggested report language to help guide the development and implementation of the Ending the HIV Epidemic Plan. This includes the importance of ensuring (1) adequate community involvement including people living with and at risk of HIV; (2) funding is distributed to those areas most in need; (3) funding for community-based organizations; and (4) the syndemics of hepatitis and STDs are addressed. We also believe it is important for the Committee to know the proposed cost of the initiative in future years, along with future savings, and the manner in which progress will be measured. We also propose that the Administration provide annual reports to the Congress on the initiative's efforts.

CDC HIV PREVENTION

CDC's Division of HIV/AIDS Prevention focuses resources on those populations and communities most affected by investing in high-impact prevention. The CDC has reported that half of people who test positive for HIV have been living with HIV more than 3 years, proving that increasing access to testing is important to end the epidemic. There is no single way to prevent HIV, but jurisdictions use a combination of effective evidence-based approaches including testing, linkage to care, education, condoms, syringe service programs, and PrEP. We urge the Subcommittee to fund CDC's HIV Prevention program at $1.012 billion, which includes $50 million for school-based HIV prevention efforts and $140 million for the Ending the HIV Epidemic Plan.

THE RYAN WHITE HIV/AIDS PROGRAM

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

The AIDS Institute requests that the Subcommittee fund the Ryan White HIV/AIDS Program at a total of $2.557 billion in fiscal year 2020, distributed in the following manner:

—Part A at $686.7 million; Part B (Care) at $437 million; Part B (ADAP) at $943.3 million; Part C at $225.1 million; Part D at $85 million; Part F/AETC at $58 million; Part F/Dental at $18 million; and Part F/SPNS at $34 million; Ending the HIV Epidemic Plan at $70 million.

COMMUNITY HEALTH CENTERS

Pre-Exposure Prophylaxis (PrEP) is a once-a-day medication that effectively prevents the transmission of HIV to an HIV negative person. PrEP is a major breakthrough in HIV prevention and is one of the best hopes we have for ending the HIV epidemic. In order to do so, PrEP must be available to all 1.1 million people who could benefit from this important drug. The Ending the HIV Epidemic Plan proposes the creation of the first Federal program to provide PrEP to people at risk of HIV. This program would be administered through the Community Health Centers Program, and we urge your Subcommittee to fund the program at the requested level of $50 million in fiscal year 2020.

MINORITY AIDS INITIATIVE

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

HIV/AIDS RESEARCH

HIV/AIDS research at the NIH is the major source for developing novel tools to treat and prevent HIV, as well as implement new techniques to get these tools to the communities most impacted. The AIDS Institute requests that your Subcommittee support $3.052 billion in funding for HIV/AIDS Research at the NIH, which is consistent with NIH's fiscal year 2020 HIV/AIDS Professional Judgment Budget. Unfortunately, the President's fiscal year 2020 Budget proposed a $424 million cut to NIH HIV/AIDS research, which we urge you to reject. We also urge you to ensure that the $6 million proposed to the Centers for AIDS Research for the Ending the HIV Epidemic Plan be new funding and not at the cost of other HIV research programs at NIH.

Additionally, we support the inclusion of report language stating that HIV/AIDS research receive increased funding proportional to the increases to NIH's total appropriations levels. This will help ensure HIV/AIDS researchers can continue to develop new tools to fight the epidemic and one day find a durable vaccine or cure for HIV.

VIRAL HEPATITIS IN THE U.S

The CDC estimates there was a 350 percent increase in new infections of HCV between 2010 and 2016. At least seventy percent of new HCV infections are a result of injection drug use. Hepatitis B (HBV) infections are also increasing, with approximately 20,000 new cases occurring in 2016. There are an estimated 1.2 million people in the United States living with HBV and 2.4 million living with HCV, yet more than half of them are unaware of their infection. Left untreated, viral hepatitis can cause liver damage, cirrhosis, and liver cancer. We now have a highly effective cure for HCV, but it only works if people are tested, diagnosed, and referred for treatment. Adding to this problem, many States in the country have also been experiencing outbreaks of hepatitis A (HAV).

CDC VIRAL HEPATITIS PREVENTION

Despite the large increase in the number of cases and the ongoing HAV outbreaks, the CDC's Viral Hepatitis program funding is only $39 million, nowhere near the estimated $316 million a December 2016 CDC professional judgment budget describes as being necessary for a national program focused on decreasing mortality and reducing the spread of the disease. Unfortunately, the President's fiscal year 2020 Budget maintains funding at the $39 million fiscal year 2019 level. Only with increased funding can we begin to address the rise in viral hepatitis and combat the impact of the opioid crisis. The AIDS Institute recommends $134 million for CDC viral hepatitis activities in order address this epidemic.

INFECTIOUS DISEASE IMPACT OF THE OPIOID CRISIS

The recent explosion of opioid use has created tremendous risk for HCV and HIV outbreaks and increasing infection rates among new groups and undoing progress toward curbing transmissions. The systems built to respond to HIV and HCV are well poised to conduct outreach, engagement, and early intervention services with individuals who use drugs. A comprehensive response to the opioid epidemic must include infectious disease prevention efforts to reduce the infectious disease consequences of the epidemic.

The SUPPORT Act of 2018 (115–H.R.6), which passed last year, authorizes funding (Sec. 7141) to enhance the Nation's response to preventing and treating infectious diseases commonly associated with injection drug use and authorizes CDC to expand surveillance for those diseases, including viral hepatitis and HIV. The AIDS Institute supports the Administration's proposed $58 million for CDC's opioid-related infectious disease elimination efforts. This would allow CDC to work collaboratively with State and local health departments to improve knowledge of the full scope of the burden of these infectious diseases.

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

THE TEEN PREGNANCY PREVENTION PROGRAM

Young people under the age of 25 account for one in five new HIV infections in the U.S. We must ensure that they, especially those in communities disproportionately impacted by HIV, have access to high quality evidence-based sexual health programs. The Teen Pregnancy Prevention Program (TPPP) funds innovative community-driven projects aimed at reducing unplanned pregnancies and increasing access to sexual health education, such as HIV prevention information. TPPP is a key tool in our HIV prevention work with young people, and we request the Subcommittee fund TPPP at $130 million in fiscal year 2020.

SEXUAL RISK AVOIDANCE/ABSTINENCE-ONLY EDUCATION

Our Nation has wasted billions of dollars funding ineffective and harmful abstinence-only programs, now rebranded as "sexual risk avoidance." These programs have little evidence of success and are stigmatizing, especially to LGBTQ and gender non-conforming young people. We urge the Subcommittee to fully defund these programs, saving taxpayer $35 million a year, and ensuring that young people are not prevented from learning about sexual health, including HIV prevention tools.

TITLE X FAMILY PLANNING PROGRAM

The Title X family planning program provides family planning and sexual health services to over 4 million people with low incomes across the Nation. Title X clinics are essential to ensuring access to family planning and sexual health services. These clinics are required to provide HIV prevention education and HIV testing onsite or by referral. We request that the Subcommittee appropriate $400 million for Title X in fiscal year 2020.

PREPARED STATEMENT OF AIDS UNITED

AIDS United fiscal year 2020 Testimony prepared for the Senate Committee on Appropriations Subcommittee on Labor, Health and Human Services, Education, and Related Agencies

As the Committee begins its important deliberations on the fiscal year 2020 Labor, Health and Human Services, Education, and Related Agencies appropriations bill, we thank you for your continued commitment to addressing HIV/AIDS in the United States and we ask that you maintain the Federal Government's commitment to safety net programs that protect public health.

In his recent State of the Union address, President Trump challenged this Congress and the Nation to end the domestic HIV epidemic by 2030. Secretary Azar championed this auspicious goal through the Department of Health and Human Service's fiscal year 2020 budget request, which calls for $291 million in increased funding for HIV prevention, care, and treatment to the domestic HIV/AIDS portfolio. We are encouraged by the Administration's increased funding request for the Ryan White HIV/AIDS Program, HIV prevention programs at the Centers for Disease Control and Prevention (CDC), and HRSA's Community Health Centers Program and urge the Committee to build upon these proposed funding increases in your fiscal year 2020 appropriations. We appreciate the call for increased funding after years of flat funding for these vital programs. However, we also encourage you to align with the Administration's stated goal to end the epidemic by providing adequate funding for AIDS research at the National Institutes of health (NIH) and other programs that protect and advance public health in fiscal year 2020 by at least matching the HIV investments proposed in the House Labor, Health and Human Services, Education, and Related Agencies Subcommittee mark-up.

We have a unique opportunity to make history. For the first time since the CDC originally reported a few HIV cases in its Morbidity and Mortality Weekly Report 38 years ago, we are able to end the HIV epidemic the United States. Scientific advances and groundbreaking HIV research have shown us that it is not only possible for people to live long, healthy lives with HIV, but that people on antiretroviral medication who have achieved an undetectable viral load cannot transmit the virus to others. Period. This knowledge alone, however, will not affect the change we need.

Over one million Americans are living with HIV, and annual HIV diagnoses continue to hover around 40,000 new HIV transmissions each year due in part to increases in injection drug use across the country that are resulting in new HIV outbreaks, especially in areas with scarce public health resources. It is only through significant Federal investment in the following programs and an unyielding commitment to providing access to the support services needed to ensure populations impacted by HIV adhere to their care and treatment that we will be able to end the HIV epidemic:

THE RYAN WHITE HIV/AIDS PROGRAM

The Ryan White HIV/AIDS Program, a payer of last resort, provides medications, medical care, and essential coverage completion services to almost 550,000 low-income, uninsured, and/or underinsured individuals living with HIV. Viral suppression, and the preventive benefits thereof, are only possible if an individual is in care and on treatment. Over 85 percent of Ryan White clients have achieved viral suppression, compared to just 49 percent of people living with HIV nationwide. This is achieved through clients' access to the high-quality, patient-centered, comprehensive care that the Ryan White Program provides, which enables clients to remain in care and on treatment.

The Ryan White Program continues to serve populations that are disproportionally impacted by HIV, including racial and ethnic minorities, who make up three-quarters of the program's clients. Almost two-thirds are living at or below the Federal poverty level. To improve the continuum of care and advance our goal of ending the epidemic, sustained funding for all parts of the Ryan White Program is critically important to ensure that people living with HIV have uninterrupted access to healthcare, medications, and services.

Funding for the Ryan White Program is critical to improving health coverage and outcomes for people living with HIV. Therefore, we urge you to fund the Ryan White Program at a total of $2.557 billion in fiscal year 2020, including the $70 million of new funding in the President's Budget Request (refer to attached chart for more detailed funding allocation requests).

PREVENTION—CDC HIV & STD PREVENTION AND SURVEILLANCE

There has been incredible progress in the fight against HIV/AIDS and other sexually transmitted diseases (STDs) over the last 30 years. Because of the efforts by CDC's National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention (NCHHSTP) and its grantees, hundreds of thousands of new infections have been averted and billions of dollars in treatment costs have been saved. This confirms that STD prevention efforts can work, but STD rates continue to rise at historic levels. Through expanded HIV testing efforts, largely funded by the CDC, the number of people who are aware of their HIV status has increased, but 15 percent of all people living with HIV do not know their status.

AIDS United is pleased that the CDC has targeted funds to fight HIV among gay and bisexual men and transgender people, including funding for pre-exposure prophylaxis (PrEP)—a highly effective prevention tool for people who are HIV-negative—plus ongoing medical care and antiretroviral treatment for people living with HIV. While we are making progress in decreasing transmissions among some women, women of color are still disproportionately affected: Black women accounted for 61 percent of all women infected in 2016, and the HIV diagnosis rate among Latinas in 2015 was more than three times that of white women.

Despite dramatic increases in STDs in recent years, funding for the CDC's STD prevention programs has not increased since 2003, leaving health departments overwhelmed and understaffed. Ending HIV must take a multifaceted approach. Increased funding for CDC's STD prevention programs will support testing, targeted prevention interventions, public education campaigns, and surveillance activities that support HIV and STD prevention outcomes. This funding supports a combination of effective evidence-based approaches including testing, linkage to care, condoms, syringe services programs, and access to PrEP.

For fiscal year 2020, we urge you to fund the CDC Division of HIV prevention and surveillance at $822.7 million, the CDC's STD division to $227.3 million, and, in accordance with the Administration's Ending the Epidemic initiative, CDC testing and connection to preventative services programs at $140 million.

HIV/AIDS RESEARCH AT THE NATIONAL INSTITUTES OF HEALTH

U.S. leadership in the global response to HIV/AIDS, particularly in research, is essential and irreplaceable; we must invest adequate resources in HIV research at the NIH. Research supported by the NIH is far-reaching and has supported advances in science as well as innovations that have led to better drug therapies and behavioral & biomedical prevention interventions well beyond HIV itself, saving the lives of millions. Specifically, NIH support proved the efficacy of PrEP, and funding from the Institutes made it possible to learn the effectiveness of treatment as prevention and has gotten us closer than ever before to identifying an effective HIV vaccine. We are appreciative of the Committee's bipartisan support of funding increases for the NIH over the course of this epidemic and urge you to direct some of these resources to continued HIV/AIDS research so that more effective HIV treatments and ultimately a cure can be realized.

We request that HIV/AIDS research at the NIH receive a total of $3.502 billion in fiscal year 2020.

ADDRESSING THE INFECTIOUS DISEASE CONSEQUENCES OF THE OPIOID EPIDEMIC

AIDS United strongly urges the Committee to remove all restrictions on Federal funds for syringe services programs, particularly in jurisdictions experiencing or at risk for HIV or viral hepatitis outbreaks associated with injection drug use. People with HIV in the United States are often affected by chronic viral hepatitis; about one-third are coinfected with either hepatitis B (HBV) or C (HCV). Over the last several years, the opioid crisis has led to concerning numbers of new infections tied to injection drug use, resulting in nearly 55,000 new hepatitis cases each year. In fact, HCV is now responsible for more deaths annually than all other reportable infectious diseases combined.

The CDC has identified 220 counties that are most vulnerable to outbreaks of HCV and HIV related to injection drug use, representing only the top 5 percent of vulnerable counties overall. At present, more than 93 percent of those 220 counties vulnerable to HIV/HCV outbreaks do not have comprehensive syringe services programs. Over the past 30 years, the CDC has collected compelling evidence of syringe services programs' effectiveness. Syringe services programs increase access to comprehensive resources such as HIV and hepatitis testing and linkage to treatment, referral to substance use treatment and assistance, behavioral health services, primary care, overdose treatment and education, hepatitis A and B vaccinations, and other ancillary services. Syringe services programs are recommended by AIDS United as a key component of the Department of Health and Human Service's response to the opioid crisis in CDC, HRSA, and SAMHSA appropriations, and as an indispensable tool in any effort to end the domestic HIV and viral hepatitis epidemics.

AIDS United urges the Committee to increase funding for the CDC Division of Viral Hepatitis activities to $134 million to ensure appropriate levels of testing, education, screening, and linkage to care.

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

FAPP

FEDERAL AIDS POLICY PARTNERSHIP

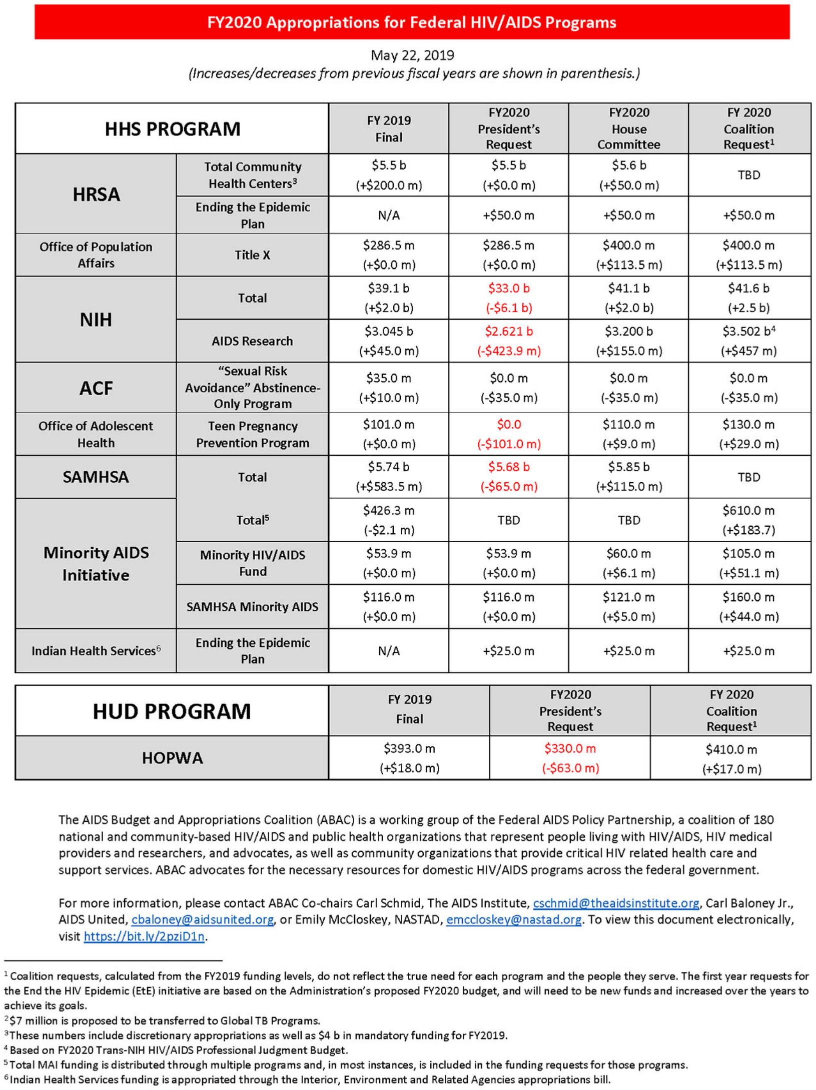
AIDS BUDGET & APPROPRIATIONS COALITION

FY2020 Appropriations for Federal HIV/AIDS Programs

May 22, 2019

(Increases/decreases from previous fiscal years are shown in parenthesis.)

HHS PROGRAM			FY 2019 Final	FY2020 President's Request	FY2020 House Committee	FY 2020 Coalition Request[1]
CDC	Total – HIV, Hep, STD, TB line		**$1.132 b (+$5.0 m)**	**$1.318 b (+186.0 m)**	**$1.335 b (+203.0 m)**	**$1.628 b (+$496 m)**
	Division of HIV/AIDS Prevention	Total	$788.7 m (+$0.0 m)	$928.7 m (+$140.0 m)	$945.6 m (+$156.9 m)	$1.012 b (+$224.0 m)
		HIV Prevention	$755.6 m (+$0.0 m)	$755.6 m (+$0.0 m)	$755.6 m (+$0.0 m)	$822.7 m (+$67.1 m)
		Ending the Epidemic Plan	N/A	+$140 m	+$140 m	+$140 m
		School Health	$33.1 m (+$0.0 m)	$33.1 m (+$0.0 m)	$50.0 m (+$16.9 m)	$50.0 m (+$16.9 m)
	Viral Hepatitis		$39.0 m (+$0.0 m)	$39.0 m (+$0.0 m)	$50.0 m (+$11.0 m)	$134.0 m (+$95 m)
	STD Prevention		$157.3 m (+$0.0 m)	$157.3 m (+$0.0 m)	$167.3 m (+$10.0 m)	$227.3 m (+$70 m)
	TB Elimination		$142.2 (+$0.0 m)	$135.2 (-$7.0 m)[2]	$152.3 m (+$10.1 m)	$195.7 m (+$53.5 m)
	Opioid Related Infectious Diseases		$5.0 m	$58.0 m (+$53.0 m)	$20.0 m ($15.0 m)	$58.0 m (+$53.0 m)
HRSA	Ryan White Program Total		**$2.319 b (+$0.0)**	**$2.389 b (+$70.0)**	**$2.435 b (+$116.4)**	**$2.557 b (+$238.3 m)**
	Part A		$655.9 m (+$0.0 m)	$655.9 m (+$0.0 m)	$677.5 m (+21.6 m)	$686.7 m (+$30.8 m)
	Part B: Care		$414.7 m (+$0.0 m)	$414.7 m (+$0.0 m)	$419.6 m (+$4.9 m)	$437.0 m (+$22.3 m)
	Part B: ADAP		$900.3 m (+$0.0 m)	$900.3 m (+$0.0 m)	$912.0 m (+$11.7 m)	$943.3 m (+$43.0 m)
	Part C		$201.1 m (+$0.0 m)	$201.1 m (+$0.0 m)	$207.6 m (+$6.5 m)	$225.1 m (+$24.0 m)
	Part D		$75.1 m (+$0.0 m)	$75.1 m (+$0.0 m)	$76.0 m (+$0.9 m)	$85.0 m (+$9.9 m)
	Part F: AETCs		$33.6 m (+$0.0 m)	$33.6 m (+$0.0 m)	$34.0 m (+$0.4 m)	$58.0 m (+$24.4 m)
	Part F: Dental		$13.1 m (+$0.0 m)	$13.1 m (+$0.0 m)	$13.3 m (+$0.2 m)	$18.0 m (+$4.9 m)
	Part F: SPNS		$25.0 m (+$0.0 m)	$25.0 m (+$0.0 m)	$25.0 m (+$0.0 m)	$34.0 m (+$9.0 m)
	Ending the Epidemic Plan		N/A	+$70.0 m	+$70.0 m	+$70.0 m



FY2020 Appropriations for Federal HIV/AIDS Programs

May 22, 2019

(Increases/decreases from previous fiscal years are shown in parenthesis.)

HHS PROGRAM		FY 2019 Final	FY2020 President's Request	FY2020 House Committee	FY 2020 Coalition Request[1]
HRSA	Total Community Health Centers[3]	$5.5 b (+$200.0 m)	$5.5 b (+$0.0 m)	$5.6 b (+$50.0 m)	TBD
	Ending the Epidemic Plan	N/A	+$50.0 m	+$50.0 m	+$50.0 m
Office of Population Affairs	Title X	$286.5 m (+$0.0 m)	$286.5 m (+$0.0 m)	$400.0 m (+$113.5 m)	$400.0 m (+$113.5 m)
NIH	Total	$39.1 b (+$2.0 b)	$33.0 b (-$6.1 b)	$41.1 b (+$2.0 b)	$41.6 b (+2.5 b)
	AIDS Research	$3.045 b (+$45.0 m)	$2.621 b (-$423.9 m)	$3.200 b (+$155.0 m)	$3.502 b[4] (+$457 m)
ACF	"Sexual Risk Avoidance" Abstinence-Only Program	$35.0 m (+$10.0 m)	$0.0 m (-$35.0 m)	$0.0 m (-$35.0 m)	$0.0 m (-$35.0 m)
Office of Adolescent Health	Teen Pregnancy Prevention Program	$101.0 m (+$0.0 m)	$0.0 (-$101.0 m)	$110.0 m (+$9.0 m)	$130.0 m (+$29.0 m)
SAMHSA	Total	$5.74 b (+$583.5 m)	$5.68 b (-$65.0 m)	$5.85 b (+$115.0 m)	TBD
Minority AIDS Initiative	Total[5]	$426.3 m (-$2.1 m)	TBD	TBD	$610.0 m (+$183.7)
	Minority HIV/AIDS Fund	$53.9 m (+$0.0 m)	$53.9 m (+$0.0 m)	$60.0 m (+$6.1 m)	$105.0 m (+$51.1 m)
	SAMHSA Minority AIDS	$116.0 m (+$0.0 m)	$116.0 m (+$0.0 m)	$121.0 m (+$5.0 m)	$160.0 m (+$44.0 m)
Indian Health Services[6]	Ending the Epidemic Plan	N/A	+$25.0 m	+$25.0 m	+$25.0 m

HUD PROGRAM	FY 2019 Final	FY2020 President's Request	FY 2020 Coalition Request[1]
HOPWA	$393.0 m (+$18.0 m)	$330.0 m (-$63.0 m)	$410.0 m (+$17.0 m)

The AIDS Budget and Appropriations Coalition (ABAC) is a working group of the Federal AIDS Policy Partnership, a coalition of 180 national and community-based HIV/AIDS and public health organizations that represent people living with HIV/AIDS, HIV medical providers and researchers, and advocates, as well as community organizations that provide critical HIV related health care and support services. ABAC advocates for the necessary resources for domestic HIV/AIDS programs across the federal government.

For more information, please contact ABAC Co-chairs Carl Schmid, The AIDS Institute, cschmid@theaidsinstitute.org, Carl Baloney Jr., AIDS United, cbaloney@aidsunited.org, or Emily McCloskey, NASTAD, emccloskey@nastad.org. To view this document electronically, visit https://bit.ly/2pziD1n.

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[1] Coalition requests, calculated from the FY2019 funding levels, do not reflect the true need for each program and the people they serve. The first year requests for the End the HIV Epidemic (EtE) initiative are based on the Administration's proposed FY2020 budget, and will need to be new funds and increased over the years to achieve its goals.

[2] $7 million is proposed to be transferred to Global TB Programs.

[3] These numbers include discretionary appropriations as well as $4 b in mandatory funding for FY2019.

[4] Based on FY2020 Trans-NIH HIV/AIDS Professional Judgment Budget.

[5] Total MAI funding is distributed through multiple programs and, in most instances, is included in the funding requests for those programs.

[6] Indian Health Services funding is appropriated through the Interior, Environment and Related Agencies appropriations bill.

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

PREPARED STATEMENT OF ALABAMA POSSIBLE

Thank you for the opportunity to share our input on the Federal appropriations process. We want to highlight how increased support to Historical Black Colleges and Universities (HBCUs) can reduce the disproportionate debt burden for student borrowers of color.

Alabama is home to the largest number of HBCUs in the Nation, and Alabama Possible is a statewide nonprofit organization that breaks down barriers to prosperity through advocacy, education, and collaboration. Our research-driven work equips Alabamians with resources to build a stronger State. We also influence public policy to ensure all Alabamians have equal opportunities to lead prosperous lives.

As a result of our FAFSA completion campaign, Cash for College Alabama, Alabama had the fourth highest improvement in FAFSA completions for the 2018–2019 FAFSA cycle. Consequently, Alabama families were able to leverage $72 million in Pell Grant dollars to continue their education after high school.[1]

The Alabama Workforce Council reports that only 43 percent of Alabamians had postsecondary credentials as of 2017, while 51 percent of job openings will require a credential by 2025. Wide disparities exist between whites and people of color; 47 percent of white working-age adults have valuable postsecondary credentials, while only 33 percent of African Americans and 24 percent of Latinos do.[2] Closing these attainment gaps should not further aggravate the already inequitable burden of student loan debt.

Completion is critical for African American borrowers, and HBCUs play an essential role on this front. In fact, despite that HBCUs represent just 3 percent of 2-year and 4-year public and private nonprofit institutions eligible for Federal dollars, they award 17 percent of all bachelor's degrees earned by African American students.[3] Furthermore, HBCUs have conferred 24 percent of the bachelor's degrees earned by black students in science, technology, engineering, and mathematics fields since the early 2000s.[4] Thus, HBCUs' track record with regards to postsecondary attainment warrants the allocation of an increased amount of taxpayer dollars.

A critical means of supporting this extraordinary attainment at HBCUs is the Empowering HBCU Grant Program in Title III–B, Section 323 of the Higher Education Act (HEA). These formula-based grant dollars are authorized for—among other things—academic resources and endowment capacity building. As noted below, this program faced decreases in appropriations from fiscal year 2012 to fiscal year 2013, fiscal year 2013 to fiscal year 2014, fiscal year 2014 to fiscal year 2015, and fiscal year 2016 to fiscal year 2017. Furthermore, the mandatory spending for this program in Title III–F, Section 371 of HEA expired in fiscal year 2019 (fiscal year 2019).[5] Thus, a significant source of funding for a demonstrably successful program is set to disappear if Congress does not act before the 2020 appropriations have concluded. The figure below depicts the appropriations negotiations outcomes for this program from fiscal year 2011 through the most recent omnibus.[6]

Strengthening HBCU Grant Program Appropriations, FY2011–2019

[In Millions]

Fiscal Year	Discretionary Appropriations	Mandatory Appropriations	Total Appropriations	Mandatory Appropriations as Percent of Total
2019	$282,420	79,730	362,150	22%
2018	279,624	79,390	359,014	22%
2017	244,694	79,135	323,829	24%
2016	244,694	79,220	323,914	25%
2015	227,524	78,795	306,319	26%
2014	223,783	78,880	302,663	26%
2013	216,056	80,665	296,721	27%
2012	227,980	85,000	312,980	27%
2011	236,991	85,000	321,991	26%

Absent a significant increase in discretionary spending in fiscal year 2020 or an agreement reached outside appropriations negotiations, the very foundation of this soon-to-be expired program will fracture. A drastic decrease in funding for this program will inevitably force HBCUs to turn to alternative revenue streams, potentially leaving students with a higher bill for tuition and fees than anticipated. Rais-

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[1] Form Your Future Tracker. National College Access Network. https://public.tableau.com/profile/bill.debaun.national.college.access.network#!/vizhome/FormYourFutureFAFSATracker-2018-19FAFSACycleThroughJune292018/CurrentWeekRanking.

[2] Success Plus Dashboard. Alabama Workforce Council. alabamaworks.com/successplus/.

[3] Williams, K. and Davis, B. (2019). Public and Private Investments and Divestments in Historically Black Colleges and Universities. American Council on Education and United Negro College Fund. https://www.acenet.edu/news-room/Documents/public-and-private-investments-and-divestments-in-hbcus.pdf.

[4] Preston, DeShawn C. (2017). Historically Black Colleges and Universities (HBCUs) Serving as a Community Cultural Wealth for African Americans Who Enroll in STEM Doctoral Programs. Clemson University. https://tigerprints.clemson.edu/all__dissertations/1931.

[5] United States Department of Education Budget Tables. https://www2.ed.gov/about/overview/budget/tables.html.

[6] Ibid.

ing tuition and fees would be especially problematic for HBCU students, who already borrow nearly twice as much as their peers enrolled at non-HBCU institutions.[7] To avoid that unacceptable outcome, we ask that, once reauthorized, mandatory appropriations for this program should be indexed to inflation to ensure at least moderate year-over-year increases, unlike the cuts resulting from the majority of the last eight budget cycles.

It is essential that the investments made in this program reflect the outstanding nature of the outcomes to which it has contributed. Thus, we urge you and your colleagues to earnestly prioritize this truly pressing need during the appropriations process. We greatly appreciate your attention to this request and would gladly make ourselves available should you require any additional information.

[This statement was submitted by Kristina Scott, JD, Alabama Possible.]

PREPARED STATEMENT OF THE ALLIANCE FOR AGING RESEARCH

Dear Chairmen Shelby and Cole and Ranking Members Leahy and Murray:

The Alliance for Aging Research (Alliance) is the leading nonprofit organization dedicated to accelerating the pace of scientific discoveries and their application to vastly improve the universal experience of aging and health. The Alliance support increased funding of basic, translational, clinical and other evidence-based research made possible by the National Institutes of Health (NIH) and the National Institute on Aging (NIA) among other Federal public health organizations. We appreciate the opportunity to submit comments on the fiscal year 2020 Labor, Health and Human Services, Education, and Related Agencies appropriations process.

The United States population is aging at an unprecedented rate and advances in biomedical research will enhance the quality of life of our Nation's older adults. We would like to thank you for your strong leadership and support of biomedical research at the NIH and NIA in fiscal year 2019. The research funded by your respective committee's will empower older adults to live longer, happier, more productive lives and reduce healthcare costs over the long term.

As you prepare the fiscal year 2020 appropriations legislation, we ask for sufficient Federal resources be dedicated to sustaining and enhancing biomedical research at the NIA, and across the NIH. 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 supports the AD Hoc Group for Medical Research's recommendation to appropriate at least $41.6 billion in fiscal year 2020 for the NIH, including funds provided through the 21st Century Cures Act for targeted initiatives. This is a $2.5 billion increase over the program funding allocated in fiscal year 2019.

In addition, we request targeted funding increases for aging and Alzheimer's disease and related dementia (ADRD) research to sustain the promising work of the NIH in these domains. Specifically, the Alliance requests a $500 million increase in the fiscal year 2020 NIH budget to support aging research, including biomedical, behavioral, and social science research efforts. Additionally, we request a minimum increase of $350 million in funding for Alzheimer's disease and related dementia research. These increases are necessary to ensure the NIH and NIA have the resources they need to address dementia and many other age-related chronic diseases.

The health services research funded by the Agency for Healthcare Research and Quality (AHRQ) helps enhance provider-patient relationships, improves patient safety, and promote higher quality care through its National Quality Measurement Clearinghouse. We respectfully request that you fund the AHRQ at the level of $460 million for fiscal year 2020. This level is proportionate with the agency's funding for fiscal year 2010 when adjusted for inflation. Additionally, with the reauthorization of the Patient-Centered Outcomes Research Trust fund this year, a strong investment from your committee is vital for preserving the core activities of the agency.

Antibiotic resistance is one of the greatest public health threats of our time. To address this crisis, we urge you to prioritize funding for the Center for Disease Control and Prevention (CDC) antibiotic resistance programs below. The Alliance for Aging Research supports $200 million in fiscal year 2020 appropriations for the CDC Antibiotic Resistance Solutions Initiative. This level of funding would allow CDC to expand healthcare-associated infections and antimicrobial resistance preven-

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[7] Saunders, K.M., Williams, K.L., & Smith, C. L. (2016). Fewer Resources More Debt: Loan Debt Burdens Students at Historically Black Colleges & Universities. United Negro College Fund Frederick D. Patterson Research Institute. http://images.uncf.org/production/reports/FINAL__HBCU__Loan__Debt__Burden__Report.pdf.

tion efforts to all 50 States. We believe that at least $32.5 million in fiscal year 2020 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 $22.75 million in fiscal year 2020 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.

Vaccine-preventable diseases cause significant illness, hospitalization, pain, disability, and death in the United States, particularly when it comes to older adults. Unfortunately, adult vaccination rates in the are dangerously low and falling short of national targets, despite the devastating effects vaccine-preventable diseases can have. Immunizations are a cost-effective form of preventive medicine that can protect the health and wellbeing of older Americans. The Alliance urges the subcommittee to provide $710 million for the National Immunization Program National Center for Immunization and Respiratory Diseases, $187.5 million for Influenza Planning and Response and $6.4 million for the National Vaccine Program Office to maintain a robust immunization infrastructure to protect the population against common vaccines preventable conditions.

Please consider the Alliance for Aging Research a resource to you and your staff. If you have questions or more additional information, please contact Ryne Carney the Alliance's Public Policy Manager at rcarney@agingresearch.org.

Sincerely.

[This statement was submitted by Susan Peschin, MHS, President and CEO, Alliance for Aging Research.]

PREPARED STATEMENT OF ALLIANT ENERGY

Chairman Blunt and Ranking Member Murray:

On behalf of Alliant Energy, I respectfully submit this written testimony for the April 9, 2019 hearing for Public Witnesses. I'm Linda Mattes, Vice President of Customer Operations at Alliant Energy, a Midwest U.S. energy provider that generates and supplies electricity and natural gas to nearly 1.4 million customers in Iowa and Wisconsin, whom we are privileged to serve.

I would like to thank the Subcommittee on Labor, Health and Human Services for the opportunity to submit testimony in support of the bipartisan Federal Low-Income Home Energy Assistance Program (LIHEAP), and more specifically to request that the committee favorably advance increased Federal funding for the program to help meet the growing need to provide energy assistance to economically vulnerable Americans.

By way of background, Alliant Energy serves our customers across a diverse region that covers more than 54,000 square miles and serves more than 1,200 communities. Whether in a city, a small town, or a rural area, expectations remain the same: our customers count on us to provide secure and reliable energy that is cost-effective.

This winter, our service territory experienced record-breaking cold air temperatures, with wind chills not seen in the 21st century in neither Iowa nor Wisconsin. Such temperatures are dangerous and can be deadly within minutes of exposure. With such extreme conditions necessitating higher-than-normal energy usage, we recognize the financial impact energy bills place on families with limited incomes.

In our service territory, approximately 48 percent of our customers have a household income of less than $50,000 a year, while nearly 22 percent of our customers have household incomes that are less than $25,000 a year. Serving economically distressed areas requires Alliant Energy to manage costs for all of our customers, and advocate for the economic health of the communities we serve.

Alliant Energy has a long and successful history of providing energy efficiency programs, partnering with community action agencies, and working with State-level agencies to help our customers manage their energy use and identify LIHEAP eligible customers. Additionally, we partner with local and State entities to help educate our customers and provide access to these important programs.

Earlier this year, Alliant Energy donated $2 million to our Hometown Care Energy Fund to provide financial help for income-eligible customers across our service area. This donation alone will help more than 5,000 Iowa and Wisconsin households with their energy bills in 2019. The Hometown Care Energy Fund is supported by Alliant Energy and its many caring customers, employees, and shareowners. We are also proud to offer confidential financial help for the elderly, disabled, and families trying to make ends meet. Alliant Energy's commitment to providing our customers with energy assistance is steadfast, which is why one of our top public policy priorities is to advocate for continued robust Federal funding for LIHEAP.

LIHEAP is not a Federal entitlement program. Every year, Congress must appropriate funding so energy assistance can be provided to families in need. As the Members of this subcommittee are aware, there is no mandatory cost-of-living or inflationary adjustment that automatically raises Federal LIHEAP funding levels despite changing economic conditions. Congress cut LIHEAP's annual appropriation almost by one-third between fiscal year 2010 and fiscal year 2017 despite the growing need for the program. Funding for LIHEAP is currently at $3.37 billion, which falls well short of meeting the energy assistance needs of low income Americans, including our customers.

We are honored to partner with the National Energy & Utility Affordability Coalition (NEUAC), a nonprofit organization comprised of diverse organizations dedicated to meeting the economic needs of low income energy consumers and to advocating for the LIHEAP program.

Iowa: https://neuac.org/wp-content/uploads/2019/02/State-Sheet-2020-Iowa.pdf.

Wisconsin: https://neuac.org/wp-content/uploads/2019/02/State-Sheet-2020-Wisconsin.pdf.

The State-level LIHEAP fact sheet links above compile household and poverty data from the U.S. Department of Health and Human Services, the U.S. Census Bureau, and the National Energy Assistance Director's Association. The data paints a stark picture, showing more than 69 percent of Iowa residents and 57 percent of Wisconsin residents, while eligible for LIHEAP, are not able to receive any energy assistance funding largely due to inadequate Federal funding.

As your committee considers funding for this critical program, Alliant Energy urges you to consider a substantial LIHEAP funding increase to provide energy assistance for economically vulnerable Iowa and Wisconsin residents. Thank you for your consideration of this request.

[This statement was submitted by Linda K. Mattes, Vice President of Customer Operations, Alliant Energy.]

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

The Alzheimer's Association and Alzheimer's Impact Movement (AIM) appreciate the opportunity to submit written testimony on the fiscal year 2020 appropriations for Alzheimer's research and public health activities at the U.S. Department of Health and Human Services. Specifically, we respectfully request a $350 million increase for Alzheimer's research at the National Institutes of Health (NIH) and $20 million for implementation of the Building Our Largest Dementia (BOLD) Infrastructure for Alzheimer's Act (Public Law 115–406) at the Centers for Disease Control and Prevention (CDC).

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

ALZHEIMER'S IMPACT ON AMERICAN FAMILIES AND THE ECONOMY

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

In addition to the suffering caused by the disease, however, Alzheimer's is also creating an enormous strain on the healthcare system, families, and Federal and State budgets. According to an NIH-funded study published in the New England Journal of Medicine, Alzheimer's is the most expensive disease in America, with costs set to skyrocket at unprecedented rates. While there are over 5 million Americans currently living with the disease, without significant action, as many as 14 million Americans will have Alzheimer's by 2050 and costs will exceed $1.1 trillion (in

2019 dollars). As the current generation of baby boomers age, near-term costs for caring for those with Alzheimer's will balloon, as Medicare and Medicaid will cover more than two-thirds of the costs for their care.

Caring for people with Alzheimer's will cost all payers—Medicare, Medicaid, individuals, private insurers, and HMOs—$20 trillion over the next 40 years. As noted in the 2019 Alzheimer's Disease Facts and Figures report, in 2019 America will spend an estimated $290 billion in direct costs for those with Alzheimer's, including $195 billion in costs to Medicare and Medicaid. Average per person Medicare costs for those with Alzheimer's and other dementias are more than three times higher than those without these conditions. Average per senior Medicaid spending is 23 times higher.

INVESTING IN ALZHEIMER'S TREATMENTS

Congress unanimously passed the National Alzheimer's Project Act (NAPA) (Public Law 111–375) in 2010, requiring the creation of an annually-updated strategic National Plan to Address Alzheimer's Disease (National Plan) 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. The primary research goal of the National Plan is to prevent and effectively treat the disease by 2025.

If America is going to succeed in the fight against Alzheimer's, Congress must continue to provide the resources scientists need to do their work. Understanding this, in 2014 Congress passed the Consolidated and Further Continuing Appropriations Act of 2015 (Public Law 113–235), which included the Alzheimer's Accountability Act (S. 2192/H.R. 4351). The Alzheimer's Accountability Act requires NIH to develop a Professional Judgment Budget focused on the research milestones established by the National Plan. This provides Congress with an account of the resources that NIH has confirmed are needed to reach the 2025 goal. The Alzheimer's Association and AIM urge Congress to fund the research targets outlined in the Professional Judgment Budget by supporting an additional $350 million for NIH Alzheimer's funding in fiscal year 2020.

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

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

It is vitally important that NIH continues to increase the investment in Alzheimer's research so we can see the same promising advances that other major diseases have realized with sustained, robust funding. An increase of $350 million in fiscal year 2020 would allow scientists to target a precision medicine approach to deliver the right treatments at the right stage of the disease; enable NIH to follow up on successful Phase I drug trials by initiating more Phase II trials focused on new therapeutic targets; and support the inclusion of Alzheimer's phenotype and environmental exposure measures in non-Alzheimer's cohorts, like cardiovascular disease and cancer, which have a wealth of data that could unlock new discovery research and accelerate cross-validation of discoveries made in Alzheimer's cohorts.

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

ADDRESSING ALZHEIMER'S AS A PUBLIC HEALTH CRISIS

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

Last year, Congress acted decisively to address Alzheimer's as an urgent and growing public health crisis through the passage of the BOLD Infrastructure for Alzheimer's Act (Public Law 115–406). This strong bipartisan law authorizes $100 million over 5 years for the CDC to build a robust Alzheimer's public health infrastructure across the country. The Alzheimer's Association and AIM urge Congress to include the full $20 million for the first year of BOLD's implementation at CDC in fiscal year 2020.

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

CONCLUSION

The Alzheimer's Association and AIM appreciate the steadfast support of the Subcommittee and its priority setting activities. We thank the Subcommittee and Congress for previous increases in Alzheimer's research activities at NIH, but the current funding level is still short of the total investment needed to meet the National Plan's primary research goal of finding a treatment or cure for Alzheimer's and other dementias by 2025. We ask Congress to continue to address Alzheimer's with the bipartisan collaboration demonstrated in previous years by providing an additional $350 million for Alzheimer's research activities at NIH and $20 million for implementation of the BOLD Infrastructure for Alzheimer's Act at CDC in fiscal year 2020.

PREPARED STATEMENT OF THE ALZHEIMER'S ASSOCIATION

+$350 million for Alzheimer's Research.—The Alzheimer's Association respectfully requests an additional $350 million at the National Institute on Aging for Alzheimer's disease research.

Alzheimer's is the most expensive disease in the United States. It is the only leading cause of death in this country with no effective means of treatment or prevention. In 2019, the United States will spend $290 billion caring for individuals with Alzheimer's and other dementias, with $195 billion of that amount paid by Medicare and Medicaid. Unfortunately, our work is only growing more urgent. More than 5 million Americans are living with Alzheimer's and, without significant action, nearly 14 million Americans will have Alzheimer's by 2050. However, estimates suggest that if a treatment became available in 2025 that delayed the onset of Alzheimer's for 5 years, Medicare and Medicaid would save a cumulative $535 billion over just the first 10 years after that treatment became available.

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

It is vitally important that NIH continues to build upon these, and many other, promising research advances. Increased funding would allow scientists to find a precision medicine approach to deliver the right treatments at the right stage of the disease; enable NIH to follow up on successful Phase I drug trials by initiating more Phase II trials for agents against new therapeutic targets; and support the

inclusion of Alzheimer's phenotype and environmental exposure measures in non-Alzheimer's cohorts, like cardiovascular disease and cancer, which have a wealth of data that could unlock new discovery research and accelerate cross-validation of discoveries made in Alzheimer's cohorts.

Proposed Report Language:

NATIONAL INSTITUTES OF HEALTH—NATIONAL INSTITUTE ON AGING

Alzheimer's Disease.—The Committee recommends an increase of $350,000,000 for NIA. In keeping with longstanding practice, the Committee does not recommend a specific amount of NIH funding for this purpose or for any other individual disease. Doing so would establish a dangerous precedent that could politicize the NIH peer review system.

Nevertheless, in recognition that Alzheimer's disease poses a serious threat to the Nation's long- term health and economic stability, the Committee expects that a significant portion of the recommended increase for NIA should be directed to research on Alzheimer's. The exact amount should be determined by scientific opportunity of additional research on this disease and the quality of grant applications that are submitted for Alzheimer's relative to those submitted for other diseases. The NIA is encouraged to continue addressing the research targets outlined in the fiscal year 2020 Professional Judgement Budget.

CENTERS FOR DISEASE CONTROL AND PREVENTION

$37 Million for Alzheimer's Public Health Rresponse.—The Alzheimer's Association respectfully requests $37 million to provide full funding for the authorization contained in the Building Our Largest Dementia (BOLD) Infrastructure for Alzheimer's Act (Public Law 115–406) and to strengthen the Healthy Brain Initiative (HBI) at CDC. Specifically, we request total program funding of $20 million for BOLD Act activities and a total of $17 million for HBI.

The recently-enacted BOLD Act would strengthen the public health infrastructure across the country by implementing Alzheimer's and related dementias interventions focused priorities such as increasing early detection and diagnosis, reducing risk, preventing avoidable hospitalizations, reducing health disparities, meeting the needs of caregivers and supporting care planning management. Activities supported by the requested $20 million would include establishing Alzheimer's Disease and Related Dementias Public Health Centers of Excellence; awarding grants, contracts or cooperative agreements to public health departments to implement public health interventions for Alzheimer's disease and related dementias; and increasing the analysis and timely reporting of data related to cognitive decline and Alzheimer's disease and related dementias.

The proposed $17 million (+$11.5 million above fiscal year 2019) for HBI would be used to (a) broaden nationwide implementation of the Public Health Road Maps, with a particular focus on reducing disparities and addressing high burden populations; (b) establish a National Public Health Alzheimer's Implementation Library to provide resources and knowledge support to States as they implement the Public Health Road Maps; (c) convene regional action institutes to bring together different departments, like transportation, aging, housing, hospitals, health systems and payers, to coordinate and work together on executing tailored Alzheimer's action plans in their communities; and (d) enable collection of cognitive decline and caregiving data through the Behavioral Risk Factor Surveillance System (BRFSS) in all 50 States, DC, and Puerto Rico over a 2-year period.

Proposed Report Language:

CENTERS FOR DISEASE CONTROL AND PREVENTION
CHRONIC DISEASE PREVENTION AND HEALTH PROMOTION

"Alzheimer's Disease.—The Committee recommendation includes an additional $20,000,000 to implement the Alzheimer's and related dementias public health programs authorized in Public Law 115–406, and includes $17,000,000 to strengthen the Healthy Brain Initiative, including implementation of the Healthy Brain Initiative Public Health Road Maps. The Committee recommendation includes sufficient funding to establish Alzheimer's Disease and Related Dementias Public Health Centers of Excellence; award grants, contracts or cooperative agreements to public health departments to implement public health interventions for Alzheimer's disease and related dementias; and increase the analysis and timely reporting of data related to cognitive decline and Alzheimer's disease and related dementias.

With this additional significant investment in addressing Alzheimer's and related dementias, the Committee strongly believes the issue should be a higher priority at CDC. Alzheimer's is one of the most prevalent chronic diseases facing our Nation and the Committee urges CDC to elevate Alzheimer's and related dementias to the Division level as with other major chronic diseases.

Office of the Secretary, General Departmental Management $250,000 for the Advisory Council on Alzheimer's Research, Care and Services: The Alzheimer's Association respectfully requests $250,000 for the Advisory Council on Alzheimer's Research, Care and Services.

The bipartisan National Alzheimer's Project Act (Public Law 111–375) requires the Secretary of HHS, in collaboration with the Advisory Council on Alzheimer's Research, Care and Services (Advisory Council), to create and maintain an annually updated National Alzheimer's Plan. The Advisory Council, made of both Federal members and expert non-Federal members, is an integral part of the planning process as it advises the Secretary in developing the annual National Alzheimer's 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.

Administration on Aging/Administration for Community Living $2 million for the National Alzheimer's Call Center: The Alzheimer's Association respectfully requests $2 million for the National Alzheimer's Call Center through the Aging Network Support Activities program at the Administration on Aging. These funds would supplement the Alzheimer's Association's nearly $5 million annual commitment of private resources to carry out this critical activity for families dealing with an Alzheimer's diagnosis.

The National Alzheimer's Call Center provides 24-hour, 7 day a week, year-round telephone support, crisis counseling, care consultation and information and referral services in over 200 languages, for persons with Alzheimer's disease, their family members and informal caregivers. Trained professional staff and master's level mental health professionals (social workers and counselors) are available at all times. In the twelve month period ending June 30, 2018, the 24/7 Helpline handled over 315,000 calls and emails through its National Contact Center and 77 chapters. These resources will go towards handling the increase in calls and complex consultations, continuing process improvements and ensuring the National Contact Center (or 24/7 Helpline) is efficient and effective.

Proposed Report Language:

Within funding for the Aging Network Support Activities, the Committee recommends $2,000,000 to continue the National Alzheimer's Call Center.

$14.7 Million for the Alzheimer's Disease Initiative (ADI).—The Alzheimer's Association respectfully requests $14.7 million for the ADI administered by the Administration for Community Living (ACL). This program provides caregiver support, provider education and public awareness for individuals with Alzheimer's disease and their caregivers. The ADI expands home- and community-based caregiver services, which have shown to be less expensive than hospital admissions and conducts outreach activities to raise awareness.

$13.4 Million for the Alzheimer's Disease Supportive Services Program (ADSSP).—The Alzheimer's Association respectfully requests $13.4 million for the ADSSP administered by the Administration for Community Living (ACL). The fiscal year 2020 funding request will allow ACL to continue to support grants that provide direct services to persons with Alzheimer's disease and their family caregivers.

PREPARED STATEMENT OF THE ALZHEIMER'S FOUNDATION OF AMERICA

NATIONAL INSTITUTES OF HEALTH

AFA is extremely grateful to the Senate Appropriations Committee for approving an increase in funding for Alzheimer's disease research at NIH for fiscal year 2019. The $425 million in additional resources for fighting Alzheimer's disease and related dementias at NIH, coupled with other increases in recent past fiscal years, will greatly increase our chances that promising research gets funded as we move closer to the goal of finding a cure or disease-modifying treatment by 2025 as articulated in the National Plan to Address Alzheimer's Disease.

Yet, just last month we heard news of another high profile failure of a stage III Alzheimer's drug trial, indicating that meaningful treatment is still some ways off and basic science into dementia—the type of research funded through NIH—remains vital to finding a cure.

AFA asks the Subcommittee to build upon past progress and continue making the battle against Alzheimer's disease a national priority. To this end, AFA urges the Subcommittee to provide an additional $350 million, for a total of approximately $2.7 billion for Alzheimer's disease clinical research at NIH in fiscal year 2020.

AFA also urges the Subcommittee appropriate at least $41.6 billion for total NIH spending in fiscal year 2020, a $2.5 billion increase over the NIH's program level funding in fiscal year 2019, as recommended by the Ad Hoc Group for Medical Research. This funding level would allow for meaningful growth above inflation in the base budget that would expand NIH's capacity to support promising science in all disciplines. It also would ensure that funding from the Innovation Account established in the 21st Century Cures Act would supplement the agency's base budget, as intended, through dedicated funding for specific programs.

CENTERS FOR DISEASE CONTROL AND PREVENTION

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

ADMINISTRATION ON COMMUNITY LIVING

AFA is requesting a $50 million increase for vital ACL programming across-the-board, including a $6.5 million increase to the Alzheimer's Disease Program for a total funding of $30 million in fiscal year 2020. In addition, AFA is requesting that the following amounts be allocated to these programs that directly impact those living with dementia:

—*National Family Caregiver Support Program (NFCSP):* NFCSP provides grants to States and territories, based on their share of the population aged 70 and over, to fund a range of supportive services that assist family and informal caregivers in caring for those with dementia at home for as long as possible, thus providing a more person-friendly and cost-effective approach to institutionalization. AFA urges that an additional $32.8 million (for a total of $214 million) be appropriated in fiscal year 2020 to support this important program.

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

—*Lifespan Respite Care Program (LRCP):* AFA urges the Committee to allocate $20 million to LRCP in fiscal year 2020. LRCP provides competitive grants to State agencies working with Aging and Disability Resource Centers and non-profit State respite coalitions and organizations to make quality respite care available and accessible to family caregivers regardless of age or disability.

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

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

PREPARED STATEMENT OF ALZHEIMER'S LOS ANGELES

Dear Chairman Blunt:

Alzheimer's Los Angeles supports a $6,000,000 increase in funding of for the Administration of Community Living's Alzheimer's Disease Programs Initiative (ADPI) for a total of $29,500,000. This program supports and promotes the development and expansion of dementia-capable home and community-based service long-term services and support systems in States and communities. In the State of California, for over 25 years, ADPI grants have funded initiatives that have built infrastructure to serve families in diverse communities, created linguistically and culturally appropriate caregiver education tools, and most recently, transformed publicly-funded healthcare systems to make them more dementia capable.

Our organization has served the greater Los Angles area including Los Angeles, San Bernardino, and Riverside counties for over 36 years, providing care, support, education, and resources that are culturally competent and linguistically accessible. We focus heavily on serving diverse communities because of the disproportionate impact of Alzheimer's on communities of color. In Los Angeles County, we expect the number of Latinos and Asians living with Alzheimer's to double by 2030, and the number of African-Americans to increase by over 30 percent. Nationally, the number of Latinos living with dementia is expected to increase more than nine times—with over 3.5 million living with the disease by 2060. ADPI funds have allowed the State of California and Alzheimer's Los Angeles, as the State's partner, to lead in the development and implementation of programs focused on improving outreach and service delivery to older adults with dementia and their family caregivers in diverse communities. This ground-breaking work has often impacted care across the Nation.

Building Infrastructure to Serve Ethnically Diverse Families Living with Dementia

The State's first program funded through this program was El Portal, an award-winning collaboration between the State of California, Alzheimer's Los Angeles and community-based organizations serving older Latinos. The collaborative created a dementia care network in East and Southeast Los Angeles, two predominantly Latino communities. This network assessed the community's needs, identified barriers to access, and developed culturally competent services in response to these needs. El Portal was highly successful, not only increasing awareness about dementia in the Latino/Hispanic community, but also in creating and connecting families to culturally and linguistically appropriate services, including five adult day care programs, seven caregiver support groups, two legal clinics, two care management sites, and a Spanish-speaking diagnostic center.

Building on the success of El Portal, the ADPI grant funds also allowed California to create a similar program reaching underserved African Americans in Los Angeles where our work represented the first-time community education had been directed toward reducing the high risk of stroke and vascular dementia in this population. The African-American-focused work on reducing risk for brain disease produced some of the Nation's first educational materials for this population and later prompted the CDC to invest funds in developing material and messaging on brain health in African Americans.

Subsequent grants enabled California to expand access to services by Asian Pacific Islander communities—building dementia care networks to serve Chinese, Japanese and Vietnamese-American people living with dementia, and later expanding to reach Korean and Filipino communities.

These ADPI- funded efforts proved so successful they were replicated in a number of other geographic regions including Puerto Rico, Seattle, New Mexico, San Diego and the San Francisco Bay Area.

Developing Caregiver Education Tools for Underserved Families

Unpaid family caregivers are unsung heroes of our Nation's long-term care system-often providing selfless care while facing increased financial burden, emotional stress, and negative impacts on their health. Investing in education, support, and resources for family caregivers is an integral part of Alzheimer's care and services. Funding through the ADPI allowed California to adopt and deliver the evidence-based caregiver education program, Savvy Caregiver, which teaches family members basic knowledge, skills and attitudes needed to be effective caregivers. Among other benefits, this program that has been proven in randomized controlled studies to reduce caregiver depression and anxiety and improve tolerance of the challenging behaviors of dementia. ADPI funds enabled California to deliver this program to over 4,000 ethnically diverse family caregivers. In addition, in partnership with the State of Texas, Alzheimer's Los Angeles piloted the Cuidando Con Respeto program, a linguistically and culturally adapted version of Savvy Caregiver for the Latino community, which has been recognized by the Rosalyn Carter Caregiving Institute and used in multiple States.

Subsequently, ADPI funds were used to enable California to fill in other gaps in the service delivery network for people living with dementia and their family caregivers including development of a program for people with dementia who live alone ; development of supports for people with intellectual disabilities who develop dementia; and, lower literacy multi-lingual education programs and materials to help families with 6th to 8th grade reading levels learn how to better manage the behavioral symptoms of dementia.

Transforming Health Care Systems

Most recently, ADPI funding to California has been key to an effort to transform the State's healthcare system, improving supports provided to people with dementia who are dually eligible for Medicare and Medicaid. The award-winning Dementia Cal MediConnect Project engaged the State of California, ten health plans, and three local Alzheimer's organizations in a partnership jointly led by the California Department of Aging and Alzheimer's Los Angeles. To date, this ground-breaking effort has improved health plans' systems of care to help assure that they detect and screen enrollees with dementia, and engage family caregivers in care planning, disease education and supports. The Project also increased health plans' workforce capacity to serve people with dementia by training over 550 care managers. Some of the results of this ADPI supported efforts include:

—A State mandate that the health plans' Health Risk Assessments ask about cognitive status and have Dementia Care Specialists on staff;
—Health plan adoption of validated cognitive impairment screening tools and family caregiver assessment tools;
—Identification, assessment, support, and engagement of family caregivers; and,
—Better connection of families and people living with the disease to home and community supports.

With ADPI support, California's effort to improve healthcare is now being replicated in Texas and other States have adopted tools and strategies from this Project.

In summary, over the past 25 years, the Federal Alzheimer's program, now known as the ADPI, has transformed the delivery of dementia care in California, particularly for the State's most vulnerable populations—the poor, the less literate, and those with linguistic and cultural barriers to accessing care. Furthermore, the work created in California has influenced care across our Nation.

We encourage the Labor Health and Human Services, Education, and Related Agencies Subcommittee to robustly fund this program. Funding of $29,500,000 will ensure that families impacted by Alzheimer's and other dementias are not only supported, but connected with culturally and linguistically appropriate resources, services, and supports from within their communities. This is the primary Federal program focused on the development of home and community-based long-term care services and supports that can help families keep their loved ones in the preferred home environment.

I thank you for this opportunity to speak about the impact and importance of the Alzheimer's Disease Program Initiative and hope that by sharing the impact of this program on our State, I can motivate you to preserve its funding and integrity.

Sincerely.

[This statement was submitted by Debra L. Cherry, Ph.D., Executive Vice President, Alzheimer's Los Angeles.]

PREPARED STATEMENT OF THE AMERICAN ACADEMY OF FAMILY PHYSICIANS

The American Academy of Family Physicians (AAFP) appreciates this opportunity to present our fiscal year 2020 recommendations. As the Nation's largest medical association of primary care physicians, we are committed to improving the health of patients, families, and communities. We urge the Committee to provide appropriations for the agencies and programs in the Department of Health and Human Services (HHS) which our members and their patients rely on for access to care, the research to improve efficacy and safety, essential family physician workforce development programs, and disease prevention and health promotion efforts. On behalf of the AAFP, representing 131,400 family physicians and medical students, I recommend that the Committee restore the discretionary budget authority for the Health Resources and Services Administration (HRSA) to the fiscal year 2010 level adjusted for inflation of $8.56 billion; provide $460 million in budget authority for the Agency for Healthcare Research and Quality (AHRQ); at least level-fund at $3.7 billion the Centers for Medicare & Medicaid Services (CMS) for program management; and include $7.8 billion for the Centers for Disease Control and Prevention (CDC).

Funding for these agencies is critical to support a strong foundation of primary care in this country. An abundance of research has clearly shown that foundational family medicine and primary care is essential to improving the health of our Nation. For example, a recent JAMA Internal Medicine study published February 18, 2019 found that every 10 additional primary care physicians per 100,000 population was associated with a 51.5-day increase in life expectancy—an increase that was more than 2.5 times that associated with a similar increase in non-primary care physicians. The inverse is also true and starker: as the density of primary care physicians decreases (11 percent decline across 10 years), there is a predictable increase in the number of deaths due to preventable causes. The cost of inaction will be an increase in morbidity and higher premature mortality. The article also noted that investment in "the National Health Service Corps, the Teaching Health Centers program, and Title VII programs, also offer the opportunity to increase the density of primary care physicians, especially in underserved areas." This pressing need for a greater investment in programs to support primary care and family medicine motivates the AAFP to strongly urge the Committee to prioritize the following programs within those HHS agencies:

National Health Service Corps—$120 Million in Discretionary Funding.—The National Health Service Corps (NHSC), administered by HRSA, plays a vital role in addressing the challenge of regional health disparities arising from physician workforce shortages by offering financial assistance to meet the workforce needs of communities designated as health professional shortage areas. We support the continuation of the $120 million the Committee provided in the fiscal year 2019 law to expand substance use disorder (SUD) treatment. The AAFP is committed to supporting the objectives of the NHSC in assisting communities in need of family physicians for their comprehensive primary care including appropriate SUD treatment. The NHSC trust fund extended by the Bipartisan Budget Act (Public Law 115–123) expires at the end of fiscal year 2019, and we are working with the broad NHSC stakeholder community to strongly urge Congress to extend it.

Title VII, § 747 Primary Care Training & Enhancement—$59 Million.—The AAFP is calling for an increase of $10 million for the Primary Care Training & Enhancement program authorized by Title VII, of the Public Health Service Act of 1963 and administered by HRSA.

Rural Residency Planning and Development Program—$15 Million.—The HRSA Rural Residency Planning and Development Program supports the development of new rural residency programs or Rural Training Tracks in family medicine, internal medicine and psychiatry. Most of the 62 million people living in a rural community or county depend on a family physician for their healthcare. The AAFP welcomes this important initiative to address rural training challenges as a way to reduce healthcare disparities facing rural communities.

Centers for Disease Control and Prevention—$7.8 Billion.—Family physicians are dedicated to treating the whole person to integrate the care of patients of all genders and every age. In addition to diagnosing and treating illness, they provide preventive care, including routine checkups, health risk assessments, immunization and screening tests, and personalized counseling on maintaining a healthy lifestyle. CDC Chronic Disease Prevention and Health Promotion funding helps with efforts to prevent and control chronic diseases and associated risk factors and reduce health disparities. We ask that the Committee provides at least $1.2 billion for CDC Chronic Disease Prevention and Health Promotion.

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

We request at least $799 million for CDC's IRD line. Within the Emerging and Zoonotic Infectious Diseases Vector-borne Diseases line, the AAFP urges increased funding to reduce the risk of tick-borne disease infections and to develop reliable diagnostic tests for tick-borne diseases which are frequently part of a differential diagnosis in primary care. The AAFP appreciates that the Committee clarified the CDC's authority to conduct research on the causes of gun violence, and we strongly urge that you provide the CDC with $50 million in fiscal year 2020 to conduct public health research into firearm morbidity and mortality prevention.

Agency for Healthcare Research and Quality—$460 Million in Budget Authority.—Primary care research, a core function of the Agency for Healthcare Research and Quality (AHRQ) translating science into improved patient care, transforming healthcare practice to meet patient and population needs, evaluating innovations to provide the best healthcare to patients, and engaging patients, communities, and practices to improve health, has suffered greatly from funding cuts. The shuttering of the National Guidelines Clearinghouse used by physicians, insurers, and health systems to access the latest evidence-based guidance about best medical practices was a direct result of inadequate Federal funding. Without increased funding, the Practice-based Research Networks (PBRN) which cultivate, conduct, support, promote, disseminate, and advocate for primary care research in practice-based settings is similarly threatened. The AAFP strongly urges the Committee to increase AHRQ funding in order to protect the PBRN and restore the research initiatives to optimize care for patients with multiple chronic conditions as well as funding for AHRQ's Center for Primary Care Research.

Office of Rural Health Policy—$305.9 Million.—The programs administered by HRSA's Office of Rural Health Policy work to reduce the unique obstacles faced by physicians and patients in rural areas. Data from the Census Bureau's American Community Survey shows that 19.3 percent of the population (about 60 million people) lives in rural areas, but CDC has found that patients in rural areas tend to have shorter life spans, and access to healthcare is one of several factors contributing to rural health disparities. Access to high quality healthcare services for rural Americans continues to be dependent upon an adequate supply of rural family physicians who perform about 42 percent of the visits that Americans in rural areas make to their physicians each year. The AAFP strongly supports an increased investment in the Office of Rural Health Policy to $305.9 million to support Rural Outreach Network Grants, Rural Health Research, State Offices of Rural Health, Rural Opioid Reversal Grants, Rural Hospital Flexibility Grants, and Telehealth as recommended by the National Rural Health Association.

Title X—$286.5 Million.—The AAFP supports continued funding for the Title X Federal grant program dedicated to providing women and men with comprehensive family planning and related preventive health services. The AAFP strongly recommends adequate funding to support Title X clinics which offer necessary screening for sexually transmissible infections, cancer screenings, HIV testing, and contraceptive care of $286.5 million in fiscal year 2020.

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

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

PREPARED STATEMENT OF THE AMERICAN ACADEMY OF NEUROLOGY

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

The American Academy of Neurology (AAN), the world's largest neurology specialty society representing over 36,000 neurologists and clinical neuroscience professionals, is strongly committed to improving the care and outcomes of persons with neurologic illness by advancing understanding of the brain and nervous system through medical research. The AAN requests increasing funding for the National Institutes of Health (NIH) to at least $41.6 billion in fiscal year 2020, an increase of $2.5 billion, including a total of $500 million to the Brain Research through Advancing Innovative Neurotechnologies (BRAIN) Initiative.

NEUROSCIENCE RESEARCH IS CRITICAL

The NIH is the world's leading funder of basic biomedical research, providing vital discoveries that can help lead to treatments and cures for neurologic diseases. Decades of basic, translational, and clinical research are necessary to develop lifesaving therapies. For example, sixty years of government funded research led to using the fava bean to develop Levodopa, the single most effective agent in the management of Parkinson's disease. Today Levodopa and other movement disorder therapies discovered through research allow Parkinson's patients to manage their symptoms. However, funding for research is a fraction of the costs to treat neurologic disease, and we are still working towards a cure. To further realize the potential of neurology-related NIH research to continue this forward momentum, we request the NIH receives at least $41.6 billion in fiscal year 2020.

BRAIN INITIATIVE

The AAN has supported the BRAIN Initiative since its inception in 2013 and recognizes the utmost importance of developing a deeper knowledge about the brain to more effectively treat neurologic disease. This multidisciplinary collaboration involving public and private partners is working to map circuits of the brain, measure electrical and chemical activity, and understand how their interplay creates unique cognitive and behavioral capabilities. Numerous AAN members currently conduct research funded by the BRAIN Initiative and appreciate the grant program's unique prioritization of innovation. For example, one BRAIN Initiative grant led to the development of a new technology that uses an electrode implanted in the brain to sense when a seizure is about to happen and responds with a small electrical current to prevent the seizure.

The Committee has steadily increased funding to ensure the success of this program. Funding for the BRAIN Initiative is supported in part by funds to the NIH Innovation Account which was created by the 21st Century Cures Act. For fiscal year 2020, the NIH Innovation Account designates $140 million for the BRAIN Initiative. In keeping with the Committee's commitment to fully fund this program, we request that a total of $500 million be appropriated to the program in fiscal year 2020, which would include $140 million from the NIH Innovation account and $360 million in further appropriations to NIH.

We appreciate your consideration of our funding requests and thank you for your ongoing commitment to medical research.

[This statement was submitted by Derek Brandt, Director, Congressional Affairs American Academy of Neurology.]

PREPARED STATEMENT OF THE AMERICAN ACADEMY OF PEDIATRICS

The American Academy of Pediatrics (AAP), a non-profit professional organization of 67,000 primary care pediatricians, pediatric medical subspecialists, and pediatric surgical specialists dedicated to the health, safety, and well-being of infants, children, adolescents, and young adults, appreciates the opportunity to submit this statement for the record in support of strong Federal investments in children's health in fiscal year 2020 and beyond. AAP urges all Members of Congress to put children first when considering short and long-term Federal spending decisions, and supports funding levels for the following programs: $50 million for Gun Violence Prevention Research, $60 million for Child Abuse Prevention and Treatment Act Plans of Safe Care Grants, $22.334 million for Emergency Medical Services for Children, $10 million for the Youth Prevention and Recovery Initiative (SAMHSA), $10 million for Pediatric Mental Health Care Access Grants, $166.14 million for National Center for Birth Defects and Developmental Disabilities, $3 million for Reducing Underage Drinking Through Screening and Brief Intervention, $5 million for Screening and Treatment for Maternal Depression, and $35 million for Lead Poisoning Prevention.

GUN VIOLENCE PREVENTION RESEARCH—CDC

Fiscal Year 2020 Request: $50 Million; Fiscal Year 2019 Level: N/A

In 2017, there were over 39,000 U.S. firearm-related fatalities.[1] federally funded public health research has a proven track record of reducing public health-related deaths, whether from motor vehicle crashes, smoking, or Sudden Infant Death Syndrome. This same approach should be applied to increasing gun safety and reducing firearm-related injuries and deaths, including suicides, and CDC research will be as critical to that effort as it was to these previous public health achievements. The dearth of research on how best to prevent morbidity and mortality from firearm-related injuries and deaths makes it difficult to implement a public health approach to addressing this public health problem.

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

Fiscal Year 2020 Request: $60 Million; Fiscal Year 2019 Level: $60 Million

The AAP appreciates the $60 million designated for CAPTA Plans of Safe Care Grants in fiscal year 2019. CAPTA is the only Federal law dedicated to primary prevention of child abuse. CAPTA requires States to refer families to child welfare services if an infant is identified at birth as affected by prenatal substance exposure, withdrawal symptoms, or a Fetal Alcohol Spectrum Disorder. Plans of safe care follow the best evidence for treating maternal substance use, including early identification and screening, appropriate treatment, consistent hospital screening of mothers and their infants, consistent hospital notifications to the child welfare system, and information sharing and monitoring across systems. These expanded requirements represent a major opportunity to address the child health impact of the opioid epidemic.

EMERGENCY MEDICAL SERVICES FOR CHILDREN—HRSA

Fiscal Year 2020 Request: $22.334 Million; Fiscal Year 2019 Level: $22.334 Million

The AAP urges the committee to maintain $22.334 million in funding for the Emergency Medical Services for Children (EMSC) Program in fiscal year 2020. Established by Congress in 1984 and last reauthorized in 2015 for 5 years, the EMSC Program is the only Federal program that focuses specifically on improving the pedi-

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[1] https://www.cdc.gov/nchs/pressroom/sosmap/firearm__mortality/firearm.htm.

atric components of the emergency medical services (EMS) system. EMSC aims to ensure that State of the art emergency medical care for the ill and injured child or adolescent pediatric services are well integrated into an EMS system backed by optimal resources, and that the entire spectrum of emergency services is provided to children and adolescents no matter where they live, attend school, or travel.

YOUTH PREVENTION AND RECOVERY INITIATIVE—SAMHSA

Fiscal Year 2020 Request: $10 Million; Fiscal Year 2019 Level: $10 Million

Access to treatment for individuals experiencing opioid use disorder (OUD) is critical, particularly given that individuals suffering from OUD have an estimated 0.65 percent risk of fatal overdose annually. The use of medication-assisted treatment (MAT) has been shown to be a relatively safe and effective treatment for OUD and improves success rates for retaining those seeking treatment. However, access to MAT for adolescents and young adults remains problematic, with recent studies showing that this population has a low likelihood of receiving MAT for OUD. The Youth Prevention and Recovery Initiative creates a competitive grant program at the Department of Health and Human Services (HHS) for healthcare providers and other entities to create substance use disorder treatment and prevention programs that include the appropriate use of MAT for adolescents and young adults.

PEDIATRIC MENTAL HEALTH CARE ACCESS GRANTS—HRSA

Fiscal Year 2020 Request: $10 Million; Fiscal Year 2019 Level: $10 Million

The AAP appreciates the $10 million in fiscal year 2019 and urges Congress to maintain funding at $10 million in fiscal year 2020 for the Pediatric Mental Health Care Access Grants established in the 21st Century Cures Act. This grant program supports the development of new statewide or regional pediatric mental healthcare telehealth access programs, as well as the improvement of already existing programs. Research shows pervasive shortages of child and adolescent mental/behavioral health specialists throughout the U.S. Integrating mental health and primary care has been shown to substantially expand access to mental healthcare, improve health and functional outcomes, increase satisfaction with care, and achieve costs savings.

NATIONAL CENTER FOR BIRTH DEFECTS AND DEVELOPMENTAL DISABILITIES—CDC

Fiscal Year 2020 Request: $166.14 Million; Fiscal Year 2019 Level: $155.56 Million

The AAP applauds the $15 million increase in fiscal year 2019 for the National Center for Birth Defects and Developmental Disabilities (NCBDDD), a center within CDC that seeks to promote the health of babies, children, and adults and enhance the potential for full, productive living. According to the CDC, birth defects affect 1 in 33 babies and are a leading cause of infant death in the United States. The center conducts important research on fetal alcohol syndrome, infant health, autism, attention deficit and hyperactivity disorders, congenital heart defects, and other conditions like Tourette Syndrome, Fragile X, Spina Bifida and Hemophilia. NCBDDD supports extramural research in every State and has played a crucial role in the country's response to the Zika virus. The center can also bolster newborn screening surveillance to improve treatment for children.

REDUCING UNDERAGE DRINKING THROUGH SCREENING AND BRIEF INTERVENTION—SAMHSA

Fiscal Year 2020 Request: $3 Million; Fiscal Year 2019 Level: Not Funded

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

SCREENING AND TREATMENT FOR MATERNAL DEPRESSION—HRSA

Fiscal Year 2020 Request: $5 Million; Fiscal Year 2019 Level: $5 Million

The AAP thanks the committee for providing $5 million in funding in fiscal year 2019 for the Screening and Treatment for Maternal Depression grant program authorized in the 21st Century Cures Act. These grants will serve to establish, improve, or maintain programs that increase screening, assessment, and treatment services for maternal depression for women who are pregnant or have given birth within the preceding 12 months. Maternal depression can lead to increased costs of medical care, inappropriate medical care, child abuse and neglect, discontinuation of breastfeeding, family dysfunction, and may adversely affect early brain development in children.

LEAD POISONING PREVENTION PROGRAM—CDC

Fiscal Year 2020 Request: $35 Million; Fiscal Year 2019 Level: $35 Million

The Academy appreciates the $35 million in fiscal year 2019 for the Lead Poisoning Prevention Program, as there is no safe level of lead exposure in children. Lead damage can be permanent and irreversible, leading to increased likelihood for behavior problems, attention deficit and reading disabilities, and a host of other impairments to developing cardiovascular, immune, and endocrine systems. Today, approximately 500,000 children are exposed to unacceptably high levels of lead, and prevention efforts are critical to protect children from its harmful effects. Adequate funding for prevention efforts can help screen more children, identify those in need of follow-up, and help reduce the impact of lead on children.

GLOBAL IMMUNIZATION—POLIO AND MEASLES/OTHER—CDC

Fiscal Year 2020 Request: $226 Million Including $176 Million for Polio and $50 Million for Measles/Other; Fiscal Year 2019 Level: $226 Million Including $176 Million for Polio and $50 Million for Measles/Other

Vaccines are one of the most cost-effective and successful public health solutions available, saving the lives of two to three million children each year. Vaccines are among the safest medical products available. The CDC provides countries with technical assistance and disease surveillance support, with a focus on eradicating polio, reducing measles deaths, and strengthening routine vaccine delivery. Global mortality attributed to measles, one of the top five diseases killing children, declined by 79 percent between 2000 and 2015 thanks to expanded immunization, saving an estimated 20.3 million lives. A global immunization campaign has reduced the number of polio cases by more than 99 percent since 1988. However, until the world is free of measles and polio, all children, even those in the United States, remain at risk. From January 1 to April 11, 2019, 555 individual cases of measles have been confirmed in 20 States, in part due to unvaccinated travelers importing the virus from parts of the world where it remains common. Only two countries had indigenous transmission of wild polio virus in 2018: Afghanistan and Pakistan. We must complete polio eradication or face a potential global resurgence, which could result in as many as 200,000 cases of polio annually within a decade.

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 2020 and beyond. If we may be of further assistance, please contact the AAP Department of Federal Affairs at pjohnson@aap.org. Thank you for your consideration.

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

PREPARED STATEMENT OF THE AMERICAN ALLIANCE OF MUSEUMS

Chairman Blunt, Ranking Member Murray, and members of the subcommittee, thank you for the opportunity to submit this testimony. My name is Laura Lott and I serve as President and CEO of the American Alliance of Museums (AAM). I respectfully request that the subcommittee make a renewed investment in museums in fiscal year 2020. I urge you to provide the Office of Museum Services (OMS) within the Institute of Museum and Library Services (IMLS) with $42.7 million, the $8 million increase recently approved by the House Appropriations Committee. This small program is a vital investment in protecting our Nation's cultural treasures, educating students and lifelong learners, and bolstering local economies around the country.

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

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

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

IMLS is the primary Federal agency that supports museums, and OMS awards grants in every State to help museums digitize, enhance and preserve collections; provide teacher professional development; and create innovative, cross-cultural and multi-disciplinary programs and exhibits for schools and the public. The fiscal year 2019 appropriation of $34.7 million, while a most welcome funding increase, still falls below its recent high of $35.2 million in fiscal year 2010. We applaud the 41 bipartisan Senators who wrote to you in support of fiscal year 2020 OMS funding.

Here are just two examples of how IMLS funding was used in 2018 to support museums' work in your communities:

—The University of Missouri in Saint Louis, Missouri received a $49,979 National Leadership Grant to support a leadership team from the university to partner with nine cultural heritage organizations, including museums, to prototype a collaborative model for internships that offers peer support and fosters mentorship to students from faculty and site coordinators. The project team will bring students, faculty and site supervisors together for a 4–5 day project team kick-off meeting to design a micro-internship program allowing diverse students to participate in 2–3 week fully-paid internships at heritage sites across the U.S. For two to three weeks, six to ten students will work in pairs at pre-selected internship sites with the support of mentors. The project activities will result in a curriculum and guide for future micro-internships that attract diverse students into the heritage museum workforce with additional opportunities and added career-building potential.

—The Woodland Park Zoo in Seattle, Washington received a $211,379 Museums for America-Community Anchors award to provide specialized training for zoo staff and volunteer mentors to design an inclusive volunteer program and remove access barriers for individuals with disabilities. The zoo will work with an advisory council composed of disability partner organizations and community members to provide expert guidance on the creation of an accessible and inclusive environment, the development of a training manual, modifications to institutional volunteer policies and procedures, and the recruitment of volunteers. A newly hired inclusion coordinator will develop and conduct a series of trainings for zoo staff and volunteers. The sustainable inclusive training model created through this project will be applicable to other cultural organizations attempting to reduce barriers for participation for all audiences and expand their volunteer programs.

In addition to these examples, I want to share with you an excerpt from the powerful live public witness testimony provided on April 9, 2019 to the House Appropriations Subcommittee on Labor, Health and Human Services, Education, and Related Agencies by a wintess on AAM's behalf:

> "My name is Mairéad Bernadita Brennan. I am one of the many beneficiaries of the Office of Museum Services' funded "Evolutions After School Program" at the Yale Peabody Museum of Natural History in New Haven, Connecticut. The Evolutions Afterschool Program is a free science and college-focused program that provides academic support and science career exploration for 120 students from New Haven and West Haven public school districts. As an aspiring first generation college student, the experience was invaluable since it exposed me to different science careers I would not have otherwise known about. Even more importantly, it normalized the idea of pursuing those careers myself. The program also introduced me to the amazing Peabody Museum staff and high school friends with whom I developed a supportive relationship with over those 4 years.
>
> Every year we were able to partake in science activities, field trips to colleges and universities, and learned to conduct research to produce our own public science exhibition. We had tremendous opportunities to visit places both inside Yale and also within the broader network of museum education programs. Evolutions students and I attended the Mid-Atlantic Youth Alliance (M.A.Y.A.) conference in the Poconos Mountains, which focused on Outdoor Education. We learned about orienteering, constellations, and biodiversity. Evolutions also visited the Maritime Aquarium in Norwalk where we were able to meet teens from their after-school program, which is based on Evolutions.
>
> I was also able to work in a laboratory internship and participate in a youth employment program called Sci. Corps that provides training on exhibit interpretation. I joined Sci. Corps and was eventually promoted to Museum Fellow, where I taught my peers innovative teaching methods, developed curriculum and supervised daily operations. My junior year, I was able to present on the benefits of hiring youth in museums at the Association of Science and Technology Center's conference in Albuquerque, New Mexico. My senior year, we worked hard to organize the next M.A.Y.A. conference that focused on environmental issues within urban communities.
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> My peers and I formed a community of growing young leaders who advanced the mission of the Peabody to bring the knowledge it holds to a broader audience. As residents of neighborhoods surrounding Yale University, we brought a unique and essential perspective and enabled the museum to better bring science and local communities together. At Evolutions, my ideas were valued, and I was able to confidently express my opinions while also collaborating with my friends in the program.
>
> Evolutions normalized the idea of pursuing the sciences while also giving us the space to discuss the barriers to access disadvantaged students face. This program was the first time my witness of inequalities and intergenerational trauma was not only taken seriously but also used to dismantle outdated ideas of who "deserves" extracurricular opportunities. I have not experienced a similar space since then, but because I participated in Evolutions as a teenager, I am confident in the validity of my experiences and how I can use it to enact real change.
>
> I continue to use the skill sets I gained from the Evolutions program and firmly believe it helped me to be more fearless in my goals. I, along with other Evolutions participants, poured years into developing, expanding, and supporting the Evolutions After School Program, which was only possible because of funding from the IMLS Office of Museum Services. Now as an alumnus of the program and a Yale University student, there is not a day that goes by where I am not using a skill set I first developed at Evolutions. I am excited to see the next chapter of Evolutions, as this new generation aims beyond my wildest expectations.
>
> Museums have a profound positive impact on society and I am living proof."

IMLS grants to museums are highly competitive and decided through a rigorous peer-review process. Even the most ardent deficit hawks ought to view the IMLS grant-making process as a model for the Nation. It should be noted that each time a museum grant is awarded, additional local and private funds are also leveraged. In addition to the dollar-for-dollar match generally required of museums, grants often spur more giving by private foundations and individual donors. Two-thirds of Museums for America grantees report that their grant encouraged additional private funding. By leveraging significant private, State, and local funding, OMS grants amplify a small Federal investment for maximum impact in the community.

Congress overwhelmingly reauthorized IMLS and its Office of Museum Services in late 2018 by enacting the Museum and Library Services Act of 2018 (Public Law No: 115–410). The legislation was passed with widespread bipartisan support by unanimous consent in the Senate and by a vote of 331 to 28 in the House, showing Congress' renewed bipartisan support for the agency's programs and a renewed commitment to its funding.

There is high demand for funding from the IMLS Office of Museum Services. In fiscal year 2018 it received 819 applications requesting nearly $120 million, but current funding has allowed the agency to fund only a small fraction of the highly rated grant applications it receives. Despite this funding shortfall, museum attendance has increased, collections are subject to increasing risk—what happened at Notre-Dame Cathedral in Paris could happen here—and museum staff members need professional development in conservation, education, and technology.

Please consider this request in the context of the essential role that museums play in our Nation, as well as their immense economic and educational impact. In closing, I highlight national public opinion polling that shows that 95 percent of voters would approve of lawmakers who acted to support museums and 96 percent want Federal funding for museums to be maintained or increased.

If I can provide any additional information, I would be delighted to do so. Thank you again for the opportunity to submit this testimony.

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

PREPARED STATEMENT OF THE AMERICAN ASSOCIATION FOR DENTAL RESEARCH

On behalf of the American Association for Dental Research (AADR), I am pleased to submit testimony describing AADR's funding requests for fiscal year 2020, which include at least $41.6 billion for the National Institutes of Health and—within NIH—$492 million for the National Institute of Dental and Craniofacial Research (NIDCR).

AADR is grateful to Congress for providing critical funding increases for most federally-funded research, including for NIH and NIDCR, in previous years' funding cycles. We recognize the difficult budget decisions Congress faces, and we appreciate that lawmakers have recognized the value that health research and public health programs provide for the health and well-being our Nation. We also recognize that for these past increases across non-defense programs, such as scientific research, to become a reality, Congress has made three 2-year deals to provide relief from austere budget caps set in the Budget Control Act of 2011.

By raising the budget caps and providing funding increases for science, members of Congress have allowed the research community to more effectively carry out their missions and meet today's needs, and we hope that trend will continue in fiscal year 2020. Despite these critical increases, the Federal research enterprise continues to play "catch up" after years of lost purchasing power due to inflation, sequestration, and other budget cuts. As the Committee drafts appropriations legislation for the coming fiscal year, AADR urges Members to prioritize Federal research, which improves the health of Americans and supports economic growth.

NIDCR—the largest institution in the world dedicated exclusively to research to improve dental, oral and craniofacial health—is among the many research institutions delivering on their promise to the American people. The Institute's research contributes to the oral and overall health of the Nation, helps to reduce the societal costs of dental care and enhances the evidence base for the dental profession. We have already seen remarkable returns on our investments in oral health research. Fluoride in water and dental sealants have led to a precipitous drop in tooth decay among children and have resulted in more Americans keeping more of their teeth for longer.[1] Since the 1950s, the total Federal investment in NIH-funded oral health research has saved the American public at least $3 for every $1 invested; we cannot afford to shortchange these programs moving forward.

In 2018, NIDCR celebrated its 70th anniversary. This milestone provided an important point of reflection and set the stage for NIDCR's future—a milestone that was particularly timely given the U.S. Surgeon General's commission of a 2020 Report on Oral Health in America. NIDCR is the lead contributing agency on the report, working alongside the U.S. Public Health Service's Oral Health Coordinating Committee, the Centers for Disease Control and Prevention (CDC), and other stakeholders. This report—beyond its findings on the State of oral health in America and

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[1] https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4212322/.

their implications—holds the same promise that the first report did in 2000: raising the visibility of oral health, putting oral health in the context of overall health, and underscoring the necessity of investing in scientific research to further improve oral health for all Americans.

Oral health, too often considered on its own, is integral to overall health. Most readily apparent in someone's day-to-day life, oral health can affect activities that may be taken for granted: the ability to eat, drink, swallow, smile, communicate or maintain proper nutrition. However, the oral cavity can also serve as a window into other potential health issues and as a place for important scientific discovery. Researchers have discovered important linkages between periodontal (gum) disease and heart disease, stroke, diabetes and pancreatic cancer. As one example, a team of intramurally- and extramurally-funded NIDCR scientists established that there is a link between rheumatoid arthritis and periodontal disease via a common oral bacterium that causes inflammation in both diseases.[2]

The research being conducted at and supported by NIDCR impacts the lives of millions of Americans. From research into how aerosols from e-cigarette vapors affect the oral microbiome to research into the prevention and treatment of HPV-related oropharyngeal cancer, which has risen significantly in recent decades, NIDCR-funded scientists are helping us to respond to visible public health concerns.

Of course, NIDCR's research is not only important from a public health and policy perspective, but it is also important from a patient perspective. NIDCR's portfolio encompasses a wide range of diseases and conditions that impede quality of life, are physically debilitating, and create a major financial and social burden. The Institute conducts research on complex systemic diseases that have a major oral health component, including TMJ; autoimmune disorders, such as Behcet's and Sjögren's Syndrome; and rare diseases, such as Cleidocranial Dysplasia (CCD).

During the 2019 AADR and Friends of National Institute of Dental and Craniofacial Research Advocacy Day on Capitol Hill, participants heard from Mr. Gaten Matarazzo, star of the Netflix series Stranger Things, who was born with Cleidocranial Dysplasia (CCD). Mr. Matarazzo cofounded "CCD Smiles," a patient advocate group, with Dr. Kelly Wosnik, and the two delivered powerful testimony about what it was like to live with a rare condition and how they have learned through their interactions with the CCD community that it is not uncommon for individuals with CCD to be undiagnosed or misdiagnosed for years. Theirs are not isolated stories. NIDCR's research is helping to establish the knowledge base to better understand rare conditions, develop treatments that are most effective for those affected, and get the latest evidence and resources into the hands of those who need it most.

This is an important point in time for dental, oral and craniofacial research. From the commission of the 2020 Surgeon General's report to the latest statistics on youth use of e-cigarettes and the opioid epidemic, dental, oral and craniofacial research are imperative to solving some of the Nation's most pressing public health issues. We implore Congress to use this opportunity and momentum to provide dental, oral and craniofacial research with the resources it needs to continue making a difference.

To do this effectively, Congress will need to work together to develop a long-term solution to our Nation's debt and deficit that does not rely on cuts to non-defense discretionary spending. Most immediately, this will entail Congress offering relief from the Budget Control Act caps to allow for these meaningful investments in science. Equally important, though, Congress must pass regular appropriations bills, on time, rather than rely on the continuing resolutions that have become so commonplace in our Federal budget process. The increased dependence on these short-term spending measures not only undermines the budget process, but it also negatively affects Federal agencies and programs, including these Federal agencies' grant recipients.

Budget trends, including continuing resolutions and attempts to increase defense spending at the expense of non-defense discretionary spending, add uncertainty in already uncertain times for Federal research spending. We hope that moving forward Congress will build on the momentum from fiscal year 2018 and continue to provide Federal research institutions with predictable and sustained funding.

In addition to supporting NIH, AADR urges Members to fund the full continuum of Federal research—from discovery to delivery. Research across the continuum is complementary and will allow us to maximize our investments. Alongside our NIH requests, our members urge you to provide $25 million for the CDC's Division of Oral Health, $40.673 million for the Title VII Health Resources and Services Administration (HRSA) programs training the dental health workforce, $460 million

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[2] www.ncbi.nlm.nih.gov/pubmed/27974664.

for the Agency for Healthcare Research and Quality (AHRQ), and $175 million in budget authority for the National Center for Health Statistics (NCHS).

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

[This statement was submitted by Maria Ryan, DDS, PhD, President, Board of Directors, American Association for Dental Research.]

PREPARED STATEMENT OF THE AMERICAN ASSOCIATION OF COLLEGES OF NURSING

ENSURING THE FUTURE OF AMERICA'S NURSING WORKFORCE

As the national voice for academic nursing, the American Association of Colleges of Nursing (AACN) represents over 543,000 nursing students and more than 45,000 nurse faculty. On behalf of its 825 member schools across the country, AACN thanks the subcommittee for its leadership and support of Nursing Workforce Development programs, which have a direct impact on the nursing pipeline and access to high-quality, evidence-based care. The association respectfully requests your continued investment in America's health in fiscal year 2020 by providing $266 million for the Nursing Workforce Development programs (Title VIII of the Public Health Service Act [42 U.S.C. 296 et seq.]), administered by the Health Resources and Services Administration (HRSA) and at least $41.6 billion for the National Institutes of Health (NIH), which includes funds provided to NIH through the 21st Century Cures Act [Public Law No: 114–255] for targeted initiatives. Within this overall NIH funding level, AACN requests $173 million for the National Institute of Nursing Research (NINR).

America's Growing Healthcare and Nursing Workforce Needs

As the largest sector of the healthcare workforce, more than four million Registered Nurses (RNs) and Advanced Practice Registered Nurses (APRNs); including Nurse Practitioners (NPs), Certified Registered Nurse Anesthetists (CRNAs), Certified Nurse-Midwives (CNMs) and Clinical Nurse Specialists (CNSs), treat and educate patients across the entire life span.[1] The nursing workforce is vital to meeting current and future healthcare demands in all areas, including rural and underserved communities. According to the Bureau of Labor Statistics, the projected RN Workforce demand is expected to increase 15 percent by 2026, representing a call for an additional 438,100 nurses.[2] Demand for most APRNs is expected to grow by 31 percent.[3]

An aging population and projected retirements from the current nursing workforce are contributing factors that impact nurse supply and demand. Nursing schools across the country are working to meet the rising demand and educate all qualified applicants interested in the profession. Though AACN reported a 3.7 percent enrollment increase in entry-level baccalaureate programs in nursing in 2018, this increase is not sufficient to meet the projected demand for nursing services, including the need for more nurse faculty, researchers, and primary care providers.[4] This is why preserving and enhancing Federal resources for Title VIII Nursing Workforce Development programs and NINR are essential to bolstering a robust nursing workforce and implementing new science that will positively impact health outcomes now and in the future.

Investing in America's Health: Requesting $266 Million for Title VIII Nursing Workforce Development Programs in Fiscal Year 2020

For over 50 years, the Title VIII Nursing Workforce Development programs have consistently and continually sustained the supply and distribution of highly-educated nurses by strengthening nursing education at all levels, from entry preparation through graduate study. Through grants, scholarships, and loan repayments programs, these indispensable Federal investments positively impact the profes-

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[1] National Council of State Boards of Nursing. (2019). Active RN Licenses: A profile of nursing licensure in the U.S. as of April 5, 2019. Retrieved from: https://www.ncsbn.org/6161.htm.

[2] U.S. Bureau of Labor Statistics. (2016). Occupational Outlook Handbook- Registered Nurses. Retrieved from: https://www.bls.gov/ooh/healthcare/registered-nurses.htm.

[3] U.S. Bureau of Labor Statistics. (2016). Occupational Outlook Handbook- Nurse Anesthetists, Nurse Midwives, and Nurse Practitioners. Retrieved from: https://www.bls.gov/ooh/healthcare/nurse-anesthetists-nurse-midwives-and-nurse-practitioners.htm.

[4] American Association of Colleges of Nursing. (2019). Nursing Shortage Fact Sheet as of April 5, 2019. Retrieved from https://www.aacnnursing.org/Portals/42/News/Factsheets/Nursing-Shortage-Factsheet.pdf.

sion's ability to serve America's patients in all communities, especially those most in need.

Educating and Sustaining a Strong Nursing Workforce:

Each of the programs that comprise Title VIII have a unique mission aimed at promoting nursing care in all communities, especially in vulnerable and underserved areas. One, in particular, the Nurse Faculty Loan Program, helps ensure we have faculty to prepare the nursing students of today to be leaders in the health profession tomorrow. According to AACN's report on 2018–2019 Enrollment and Graduations in Baccalaureate and Graduate Programs in Nursing, U.S. nursing schools turned away more than 75,000 qualified students, and pointed to a shortage of faculty and/or clinical preceptors as a primary reason for not accepting all qualified applicants into their programs.[5] The Nurse Faculty Loan Program helped fill this critical need by awarding grants to 84 schools, supporting 1,998 nursing students pursuing a degree to become nurse faculty during the 2016–2017 Academic Year.[6] Among those graduating trainees, 92 percent intend to teach nursing.[7] This is just one program under Title VIII that provides invaluable support to nursing education, practice, and retention. To ensure the stability of our nursing workforce, our total request of $266 million would support all Title VIII programs, including:

—Advanced Nursing Education (Sec. 811), which includes the Advanced Education Nursing Traineeships and Nurse Anesthetist Traineeships;
—Nursing Workforce Diversity (Sec. 821);
—Nurse Education, Practice, Quality, and Retention (Sec. 831);
—NURSE Corps Loan Repayment and Scholarship Programs (Sec. 846);
—Nurse Faculty Loan Program (Sec. 846A); and
—Comprehensive Geriatric Education (Sec. 865).

The Importance of Nursing Science: Requesting $173 Million for National Institute of Nursing Research (NINR)

The healthcare community must continuously investigate and research new methods to ensure that we are providing the best care possible. As one of the 27 Institutes and Centers at NIH, NINR plays a vital role in improving care and is on the cutting edge of new innovations that impact how nurses are educated and how they practice. Nursing scientists are moving the field forward in areas as diverse as genomics, big data, precision health, and data science, often working with other health professionals. Additionally, NINR allocates a generous portion of its budget to educating nurse researchers, many of whom also serve as nurse faculty.[8] This ensures the sustainability and longevity of nursing research.

Strong investments in Title VIII Nursing Workforce Development programs and NINR have a direct impact on the nursing pipeline and patient access to high-quality, evidence-based care in all communities across the Nation. AACN respectfully requests continued support in fiscal year 2020 of $266 million for the Title VIII Nursing Workforce Development programs and at least $41.6 billion for the National Institute of Health, which includes $173 million for the National Institute of Nursing Research. Together, we can ensure that such investments promote innovation and improve healthcare in America.

[This statement was submitted by Ann H. Cary, PhD, MPH, RN, FNAP, FAAN, Board Chair, American Association of Colleges of Nursing.]

Prepared Statement of the American Association of Colleges of Osteopathic Medicine

The American Association of Colleges of Osteopathic Medicine (AACOM) leads and advocates for the full continuum of osteopathic medical education to improve the health of the public. Founded in 1898 to support and assist the Nation's osteo-

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[5] American Association of Colleges of Nursing. (2019). Nursing Shortage Fact Sheet as of April 5, 2019. Retrieved from https://www.aacnnursing.org/Portals/42/News/Factsheets/Nursing-Shortage-Factsheet.pdf.

[6] Department of Health and Human Services Fiscal Year 2019 Health Resources and Services Administration Justification of Estimates for Appropriations Committees. https://www.hrsa.gov/sites/default/files/hrsa/about/budget/budget-justification-fy2019.pdf.

[7] Department of Health and Human Services Fiscal Year 2019 Health Resources and Services Administration Justification of Estimates for Appropriations Committees. https://www.hrsa.gov/sites/default/files/hrsa/about/budget/budget-justification-fy2019.pdf.

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

pathic medical schools, AACOM represents all 35 accredited colleges of osteopathic medicine—educating nearly 31,000 future physicians, 25 percent of all U.S. medical students—at 55 teaching locations in 32 U.S. States, as well as osteopathic graduate medical education professionals and trainees at U.S. medical centers, hospitals, clinics, and health systems.

AACOM strongly supports restoring funding for discretionary Health Resources and Services Administration (HRSA) programs to $8.56 billion; total funding of $690 million for key priorities in HRSA's Title VII and Title VIII programs under the Public Health Service Act, including adequate funding for the Centers for Excellence (COE), Health Careers Opportunity Program (HCOP), Scholarships for Disadvantaged Students (SDS) Program, Geriatrics Education Centers (GECs); $67 million for the Area Health Education Centers (AHECs) Program; $59 million for the Primary Care Training and Enhancement (PCTE) Program; $15 million for the Rural Residency Planning and Development Program; long-term sustainable funding for the Teaching Health Center Graduate Medical Education (THCGME) Program; at least $120 million in level funding for the National Health Service Corps (NHSC) and extension of the trust fund; a minimum of $41.6 billion for the National Institutes of Health (NIH); and $460 million in budget authority for the Agency for Healthcare Research and Quality (AHRQ).

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

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

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

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

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

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

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

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

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

AACOM continues to strongly support the long-term sustainment of the THCGME Program, which provides funding to support primary care medical and dental residents training in community-based settings. The majority of currently-funded medical residency programs are osteopathic or dually-accredited (DO/MD). Currently, there are more than 700 residents being trained in 56 HRSA- supported THC residencies in 23 States. According to HRSA, physicians who train in teaching health centers (THCs) are three times more likely to work in such centers and more than twice as likely to work in underserved areas. The continuation of this program is critical to addressing primary care physician workforce shortages and delivering healthcare services to underserved communities most in need. AACOM is pleased that Congress supported this highly successful bipartisan program by extending it for fiscal years 2018 and fiscal year 2019 through the Bipartisan Budget Act of 2018 (Public Law 115–123). However, this program will expire on September 30. Stable funding is necessary for the THCGME Program to continue to expand and increase the number of physicians that work in communities of need. AACOM strongly supports the continuation of and permanent funding for the THCGME Program and will continue to work with Congress to support a sustainable and viable funding mechanism for the continuation beyond fiscal year 2019. Furthermore, we strongly support that the program's funding continues as mandatory funding beyond fiscal year 2019.

The NHSC supports physicians and other health professionals who practice in health professional shortage areas across the U.S. The NHSC notes that a field strength of more than 11,400 primary care clinicians are providing services nationwide in health professional shortage areas in fiscal year 2019. While we were pleased to see a 2-year extension of this program per the Bipartisan Budget Act of 2018 (Public Law 115–123), stable funding is necessary for the continuation of this critically effective program. Therefore, AACOM supports the stability of the NHSC by requesting at least $120 million in level funding for the NHSC and extension of the NHSC trust fund, which expires at the end of this fiscal year.

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 $41.6 billion for the NIH.

AHRQ plays an important role in producing the evidence base research needed to improve our Nation's health and healthcare. The incremental increases for AHRQ's Patient Centered Health Research Program in recent years will help AHRQ generate more of this research and expand the infrastructure needed to increase capacity to produce this evidence; however, more investment is needed. AACOM recommends $460 million in budget authority for AHRQ. This investment will preserve AHRQ's current programs while helping to restore its critical healthcare safety, quality, and efficiency initiatives. Additionally, AACOM opposes the consolidation of AHRQ into the NIH.

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

[This statement was submitted by 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 2020 appropriations for the National Institutes of Health (NIH). AAI recommends an appropriation of at least $41.6 billion for fiscal year 2020 to enable NIH to fund critically important new and ongoing immunological research, support the current—and next—generation of biomedical researchers, and ensure continued U.S. leadership in basic, translational, and clinical research.

THE RECENT HISTORY (WITH A NOBEL PRIZE)—AND THE EXCITING FUTURE—OF IMMUNOLOGY

For more than a century, the immune system had been defined by its role protecting against infectious agents, such as viruses, bacteria, and parasites, that cause disease. That understanding has evolved dramatically. Research has since demonstrated that the immune system can also be harnessed to great purpose: it can kill malignant tumors, manage autoimmune diseases, and promote healing.

In 2018, the Nobel Prize in Physiology or Medicine was awarded to two AAI members, American immunologist and NIH grantee James Allison, Ph.D., and Japanese immunologist Tasuku Honjo, M.D., Ph.D., for their groundbreaking discovery that the immune system's natural brakes, which prevent excessive harm to the body's own cells, can be released, allowing immune cells to attack and kill tumor cells. This key finding has led to the development of immunotherapy agents known as checkpoint inhibitors, which have now been approved by the Food and Drug Administration (FDA) for the treatment of several solid tumors and blood cancers.[1] According to the Nobel Committee, this "entirely new principle for cancer therapy"... "constitute[s] a landmark in our fight against cancer."[2] These Nobel Laureates, and many other AAI members and scientists, have built on this discovery to help develop drugs and therapies that are not only transforming how we prevent, treat, and potentially cure several types of cancer, but are also showing similar promise for many other diseases, including rheumatoid arthritis, type 1 diabetes, and inflammatory bowel disease.[3]

The immune system, once thought to be a discrete system, has been shown to be a complex network of cells and organs that has an impact on virtually every other organ of the body and plays a significant role in preventing, contracting, and fighting innumerable infectious, autoimmune, and chronic diseases, including Alzheimer's disease, cardiovascular disease, HIV/AIDS, influenza, measles, tuberculosis, Ebola, and other public health threats. This progress has led to a greater understanding of the immune system, and the recognition that immune system-driven inflammation can not only promote healing, but if overexuberant, can also exacerbate human disease.

Recently, significant developments in immunology research include:

—Immunotherapy: Although immense progress has been made to use the immune system to kill cancer cells, much research is still needed to improve on existing, and develop new, immunotherapies. For example, not all tumors appear susceptible to immune cell killing, and NIH-funded research continues to investigate how to address this challenge.[4] In addition, because not all patients benefit from immunotherapy, there is significant effort underway to understand why and when this treatment is effective.[5] Finally, because certain tumors appear to become resistant to some immunotherapy treatments, research to discover next generation approaches is necessary.[6]

—Universal influenza vaccine: Despite the existence of a seasonal influenza virus (flu) vaccine, flu remains a major cause of disease, with an estimated 9.3 to 49 million illnesses and 12,000 to 79,000 deaths annually in the United States.[7] Although vaccination is still the best way to protect against getting sick, the current flu vaccine is suboptimal in part because it must be re-administered annually and does not induce broad cross-protection that would provide immunity against newly emerging flu strains that have pandemic potential. NIH is supporting the development of a universal flu vaccine, which has the potential to provide broad protection for all age groups against many flu strains.[8] NIH-sponsored clinical trials of universal flu vaccine candidates have been launched in 2018 and 2019.[9]

—Discovery of immune cell infiltration into the brain: Historically the brain has been described as an immuno-logically privileged site, in part because of the apparent lack of classical lymphatic vessels throughout the body that allow immune cells to circulate. However, meningeal lymphatic vessels were discovered in 2015, earning a "Breakthrough of the Year" nomination by Science magazine.[10] This discovery confirmed a connection between the immune and nervous systems which had not been previously recognized. A 2018 NIH-funded study then showed microscopic "tunnels" or vessels used to transport immune cells directly to sites of brain injury, providing ways for immune cells to contribute to healing from the injury. Further research is needed to determine whether these

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[1] https://www.fda.gov/drugs/informationondrugs/approveddrugs/ucm279174.htm.

[2] https://www.nobelprize.org/prizes/medicine/2018/press-release/.

[3] https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4896612/; https://www.ncbi.nlm.nih.gov/pubmed/28260183; https://www.ncbi.nlm.nih.gov/pubmed/29624476.

[4] https://www.ncbi.nlm.nih.gov/pubmed/28159861.

[5] https://jamanetwork.com/journals/jama/fullarticle/2719519.

[6] https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5391692/.

[7] https://www.cdc.gov/flu/about/disease/burden.htm.

[8] https://www.niaid.nih.gov/news-events/niaid-unveils-strategic-plan-developing-universal-influenza-vaccine.

[9] https://www.niaid.nih.gov/news-events/niaid-sponsored-trial-universal-influenza-vaccine-begins; https://www.nih.gov/news-events/news-releases/nih-begins-first-human-trial-universal-influenza-vaccine-candidate.

[10] https://www.nih.gov/news-events/nih-research-matters/lymphatic-vessels-discovered-central-nervous-system; http://science.sciencemag.org/content/350/6267/1458.

> newly discovered vessels may be useful for drug delivery in the future for stroke, Alzheimer's, and other brain diseases, or whether they could be harmful by contributing to immune damage to the brain.[11]

As described in part in the examples above, immunologists have made extraordinary progress, but there is still much to do. The next series of breakthroughs will be achieved only with strong Federal support.

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

As the Nation's major funding agency for biomedical research, NIH distributes approximately 80 percent of its budget to more than 300,000 researchers at about 2,500 universities, medical schools, and other research institutions in all 50 States, the District of Columbia, several U.S. territories, and internationally.[12] NIH also devotes about 10 percent of its budget to supporting approximately 6,000 additional researchers and clinicians who work at NIH facilities located in Maryland, Arizona, Montana, and North Carolina.[13] By supporting researchers and laboratories across the Nation, NIH funding not only draws on the ideas of the best scientists in the country, but also strengthens State and local economies; in 2018, NIH funding supported more than 433,000 jobs across the U.S.[14]

The research generated by NIH funding is also critically important to the Nation's highly successful pharmaceutical industry: according to a 2018 report published in the Proceedings of the National Academies of Sciences, NIH-funded research contributed to all 210 of the new drugs approved by the FDA from 2010–2016.[15] This may be the strongest evidence to date that NIH-funded basic research is an essential and irreplaceable part of the biomedical research pipeline, leading to lifesaving and life-changing new drugs.

NIH also serves as an indispensable scientific leader both in the U.S. and internationally. The steward of more than $39 billion in Federal funds, NIH keeps our Nation's leaders apprised of scientific advancements, research priorities, and emerging threats, and works to ensure that taxpayer dollars are properly and prudently spent. It oversees and establishes standards for the conduct of scientific research at academic institutions in the U.S. NIH also develops and sustains collaborations between the U.S. and other nations to work toward common goals, and between the Federal Government and the private sector, including the pharmaceutical, biotechnology, and medical device industries, which rely on NIH-supported basic research to provide a foundation of new knowledge upon which they can build.

FUNDING INCREASES HAVE RESTORED SOME, BUT NOT ALL, OF NIH'S PURCHASING POWER

Through generous, needed increases of $3 billion in fiscal year 2018 and $2 billion each in fiscal year 2016, fiscal year 2017, and fiscal year 2019 (including supplemental funding to support initiatives authorized by the 21st Century Cures Act), this subcommittee and the full Congress have helped restore some of the lost purchasing power that NIH experienced following years of insufficient budgets and erosion from biomedical research inflation; once ~25 percent below its peak funding level (2003), the gap has eased to ~9 percent. Robust funding increases will continue to be needed to close this gap and allow the research enterprise to grow to meet current opportunities. As the baby boom generation continues to retire, it is even more urgent that we ensure a dynamic research environment that will allow for the training, development, and support of our next generation of researchers, doctors, professors, and inventors. Timely, robust funding increases for NIH and other science agencies would bolster confidence among current and emerging American researchers who are unsure about the future of academic science.

CONCLUSION

AAI greatly appreciates the subcommittee's strong, continuous bipartisan support for NIH and urges an appropriation of at least $41.6 billion for fiscal year 2020. Such a robust increase in regular appropriations, combined with funding the 21st

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[11] https://www.ninds.nih.gov/News-Events/News-and-Press-Releases/Press-Releases/Researchers-unearth-secret-tunnels-between-skull.

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

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

[14] http://www.unitedformedicalresearch.com/advocacy__reports/nihs-role-in-sustaining-the-us-economy-2019-update/.

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

Century Cures Act initiatives to their fully-authorized fiscal year 2020 levels, will continue to strengthen NIH's ability to fund research that advances our fundamental knowledge of biology, support talented scientists and trainees pursuing research careers in the United States, and provide hope to all who are impacted by disease or disability.

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

PREPARED STATEMENT OF THE AMERICAN ASSOCIATION OF NEUROMUSCULAR & ELECTRODIAGNOSTIC MEDICINE

FISCAL YEAR 2020 RECOMMENDATIONS

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

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

—Please continue to provide meaningful funding increases for efforts to improve health outcomes for patients affected by neuromuscular conditions; most notably medical research at the National Institutes of Health and public health activities (such as the National Neurological Diseases Surveillance System) at the Centers for Disease Control and Prevention.

Chairman Blunt, Ranking Member Murray, and distinguished members of the Subcommittee, thank you for the opportunity to present the views of the American Association of Neuromuscular & Electrodiagnostic Medicine (AANEM) during the consideration of fiscal year 2020 LHHS appropriations. The challenges and opportunities that I will review today are not unique to AANEM, but impact a variety of medical professional societies and patient communities who rely on proper EDX testing. My comments are provided in the interest of spotlighting serious issues that continue to undermine patient care and waste Federal healthcare resources, while advancing policy tools to efficiently and effectively address these issues. In this regard, please consider the AANEM a resource moving forward. Thank you again for this important opportunity.

ABOUT AANEM

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

ABOUT EDX MEDICINE

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

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

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

ABOUT EDX FRAUD AND ABUSE

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

COMMON FRAUD SCHEMES

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

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

NCS with EMG Testing.—A complete EDX examination typically involves both NCS and EMG studies, with NCS testing exclusively required in a small number of cases. However, since needle EMG is an invasive procedure and bad actors are relying on a technician, a high rate of NCS-only studies is a hallmark of fraud and abuse.

STATEMENT OF AANEM MEMBER DR. VINCE TRANCHITELLA

New NCS codes became effective on January 1st, 2013. The new codes were developed as a direct response to fraudulent activity that resulted in the exponentially increased use of NCS. Unfortunately, the new NCS codes failed to have the desired effect. In the past 3 years alone, I have reviewed at least 20 EDX medicine fraud cases, involving multiple providers each, affecting thousands of patients. Nine of these cases involved providers in the New York City region. Most of the providers I reviewed did not receive appropriate training in EDX Medicine yet were still regularly conducting studies.

RECENT EXAMPLES

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

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

In a case from Louisiana, I reviewed more than 25 patients charts in detail and found that in no case had the EDX study been performed correctly (resulting in no patients being given correct diagnoses). This case was especially remarkable in that the practitioner perpetrating the fraud was reviewing the cases from his couch in the evenings and billing more than 1.8 million dollars each year!

CURRENT OPPORTUNITIES

CMS, FBI, and the HHS OIG have been doing tremendous work to root out fraud and abuse in EDX medicine, but these dedicated public servants are limited by the constraints of the current pay-and-chase model. Additional resources for ongoing CMS efforts to address healthcare fraud and abuse will facilitate incremental improvements and further protect patients, but modernization is needed as well. Over recent appropriations cycles, Congress has called on CMS to work with the EDX community on innovative solutions that could better identify bad actors conducting EDX testing or simply prevent payments for improper studies before they are made. Please continue to work with CMS through the fiscal year 2020 appropriations process to recommend greater community collaboration and to encourage meaningful and timely progress in the area of EDX fraud and abuse.

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

Prepared Statement of the American Chemical Society

Dear Chairman Blunt and Ranking Member Murray:

The American Chemical Society (ACS) urges you to support robust funding for the National Institutes of Health (NIH) when the Labor, Health and Human Services, Education and Related Agencies appropriations bill is written. The work of the National Institute of General Medical Sciences (NIGMS), National Center for Advancing Translational Sciences (NCATS), and the National Institute of Biomedical Imaging and Bioengineering (NIBIB) are particularly vital to advancing medical research and promoting the health of the American people, but remains unfamiliar to many Americans compared to disease-specific centers and institutes. Through its research grants and fellowship programs, NIH also plays an integral role in attracting and training the young scientists and engineers who will help the United States remain a leader in medical research and technology. Investing in the NIH now ensures a future of well-trained scientists and continued medical advances.

As an organization of over 150,000 chemical scientists and engineers, ACS understands the benefits of sustained, predictable funding for NIH to the research community. For example, NIGMS, which has supported more than 50 Nobel laureates, funds high-quality, non-disease-specific basic research, laying the scientific foundation for an array of advances in disease prevention, diagnosis, and treatment. NIBIB supports basic research and training through investigator-initiated grants, contracts, program project and center grants, and career development and training awards. The Institute also specializes in the development and application of cutting-edge technologies based upon engineering, mathematics, and the physical sciences for the solution of challenges intersecting biology and medicine. NCATS focuses on ensuring that ground-breaking research from universities reaches the people who need it by streamlining the pipeline from basic research to applied research to medicines and techniques used in medicine. NIGMS, NIBIB, and NCATS all contribute to the vibrant health and medical research community in the United States and we realize that the return of Budget Control Act caps hampers the ability of appropriators to invest in critical Federal priorities. We urge Congress to devise a new bipartisan budget agreement that raises nondefense discretionary spending caps to ensure continued scientific innovation and progress in medical research. We believe that any agreement on discretionary caps should provide comparable defense and nondefense increases. We also request a funding allocation for the Labor-HHS Subcommittee that allows for the sustained investment in NIH.

Sincerely.

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

PREPARED STATEMENT OF THE AMERICAN COLLEGE OF CARDIOLOGY

The American College of Cardiology (ACC) commends Congress for boosting funding for the National Institutes of Health (NIH) and Centers for Disease Control and Prevention (CDC) in fiscal year 2018 and fiscal year 2019, and mandatory increases for the NIH as part of the 21st Century Cures Act and the Bipartisan Budget Act of 2018. These significant investments will help spur the development and implementation of medical innovations. To continue this important progress and ensure future medical research advancements in fiscal year 2020 and beyond, ACC urges members of Congress to appropriate the following funds toward agencies doing vital work in cardiovascular disease (CVD) treatment and prevention: $3.71 billion for the National Heart Lung & Blood Institute (NHLBI) and $2.36 billion toward the National Institute of Neurological Disorders & Stroke (NINDS) to increase the NIH's purchasing power and preserve U.S. leadership in research; $160 million toward the CDC's Division for Heart Disease and Stroke Prevention to strengthen heart disease prevention efforts at State and local levels, $5 million toward CDC's Million Hearts to prevent 1 million heart attacks and strokes by 2022, $45.6 million toward CDC's WISEWOMAN to help uninsured or under-insured women prevent or control heart disease, $10 million toward CDC congenital heart research to study its effects over the patient's lifespan, and $310 million toward CDC's Office on Smoking and Health to maintain the program's cost-effective tobacco control efforts.

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

CVD, a class of diseases that includes diseased blood vessels, structural problems, and blood clots, continues to be the leading cause of death among men and women in the United States and is responsible for 1 in every 4 deaths.[1] More than 92 million Americans currently suffer from some form of CVD—nearly one-third of the population—but it remains one of the most underfunded deadly diseases, as the NIH only invests 4 percent of its research dollars on heart research.[2] Despite reduced capacity to fund grants and new discoveries over the last decade, the NIH continues to enhance and save millions of lives. The heart disease death rate has continued to drop since the 1970s[3] due to scientific advances and improved heart medications and procedures—but to meet the challenges of an aging population, rising obesity rates and unhealthy diets, the NIH must maintain its place at the forefront of medical innovation for years to come. The NHLBI, the third-largest institute at the NIH, conducts research related to heart, blood vessel, lung, and blood diseases, generating drugs for lowering cholesterol, controlling blood pressure, and dissolving blood clots. These biomedical advancements have contributed to a 71 per-

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

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

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

cent[4] decrease in death rates due to cardiovascular disease. NHLBI's recent groundbreaking research found that more intensive management of high blood pressure in people 50 years and older reduces cardiovascular events by almost 25 percent.[5] We recommend that NHLBI be funded at $3.71 billion to maintain current activities and investment toward new research and emerging technologies related to heart disease.

NINDS conducts research on brain and nervous system disorders, including stroke prevention and treatment. Coronary heart disease and stroke share many of the same risk factors such as high cholesterol levels, high blood pressure, smoking, diabetes, physical inactivity, and being overweight or obese. The NINDS Stroke Clinical Trials Network develops high-quality, multi-site clinical trials focused on key interventions in stroke prevention, treatment and recovery. We recommend that NINDS be funded at $2.36 billion to enhance its existing initiatives and explore new priorities in stroke prevention.

The CDC plays a vital role in protecting public health through healthy lifestyle promotion and educational activities designed to curb non-infectious diseases such as obesity, diabetes, stroke, and heart disease. The CDC Division for Heart Disease and Stroke Prevention supports efforts to improve cardiovascular health by promoting healthy lifestyles and behaviors, healthy environments, and access to early detection and affordable treatment. The division engages with local and State health departments, and a variety of other partners, to provide funding and resources, conduct research, track risk factors, and evaluate current programs and policies relating to heart disease. We recommend that the CDC Division for Heart Disease and Stroke Prevention be funded at $160 million to continue its prevention activities among the most vulnerable communities.

The CDC Division for Heart Disease and Stroke Prevention promotes education and awareness for peripheral arterial disease (PAD). PAD is a common circulatory problem in which one or more arteries supplying blood to the legs, arms, or abdomen become blocked. PAD affects 200 million patients worldwide and has a higher prevalence than all cancers combined, but the disease is substantially underdiagnosed since most experience few symptoms until irreversible damage is done and may result in amputation. We encourage the CDC to enhance education and awareness activities that promote early diagnosis of PAD and ultimately reduce the number of unnecessary amputations that adversely impact millions of lives.

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

CDC's WISEWOMAN initiative provides more than 165,000 under-insured, low-income women ages 40–64 with services to help reduce heart disease and stroke risk factors. Heart disease ranks as the leading cause of death for women. Only 1 in 5[6] women believes heart disease is her greatest health threat, and 11 percent[7] of women remain uninsured. We recommend that $45.6 million be allocated for WISEWOMAN to provide preventive health services, referrals to local healthcare providers, lifestyle programs, and counseling in all 50 States.

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

Programs within CDC's Office on Smoking and Health (OSH) work to prevent smoking among young adults and eliminate tobacco-related health disparities in dif-

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

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

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

ferent population groups. In 2012, OSH launched the national tobacco education campaign, Tips from Former Smokers, which has motivated more than 5 million[8] people to quit smoking, with at least 400,000 quitting permanently.[9] While these programs have proven effective in tobacco cessation and prevention, more than 480,000 people still die every year from causes attributable to smoking, and 33 percent of those deaths stem from heart disease.[10] We recommend that OSH be funded at $310 million to continue leading the Nation's efforts in preventing chronic diseases caused by tobacco use.

On behalf of our members who work to prevent and treat CVD, ACC would like to thank members of Congress for supporting medical innovation as we continue the fight against heart disease. Stable funding for 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 funding for NIH and CDC funding to protect the health of future generations.

[This statement was submitted by Richard J. Kovacs, MD, FACC, President, American College of Cardiology.]

PREPARED STATEMENT OF THE AMERICAN COLLEGE OF OBSTETRICIANS AND GYNECOLOGISTS

The American College of Obstetricians and Gynecologists (ACOG), representing more than 58,000 physicians and partners dedicated to advancing women's health, is pleased to offer this statement to the Senate Committee on Appropriations, Subcommittee on Labor, Health and Human Services, Education, and Related Agencies. We thank Chairman Blunt, Ranking Member Murray, and the entire Subcommittee for this opportunity to provide comments on some of the most important programs to support and advance women's health.

ACOG commends Congress for making great strides in advancing research and data collection to advance the health of women and families. Looking ahead, we urge you to make funding of the following programs and agencies a priority in fiscal year 2020:

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

The United States has the highest rate of maternal mortality and severe morbidity of any developed country. The Safe Motherhood Initiative at CDC works with State health departments to collect information on pregnancy-related deaths, give technical assistance to maternal mortality review committees, track preterm births, and improve maternal outcomes through Maternity and Perinatal Quality Collaboratives. Important strides have been made as 45 States currently have or are in the process of implementing State maternal mortality review committees, however, we must continue to build on these improvements. ACOG requests you fund the Safe Motherhood Initiative at $58 million, including $12 million to help States expand or establish maternal mortality review committees, and $2 million for State-based perinatal quality collaboratives.

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

Women represent half of the US population. As such, conditions and diseases that are specific to women's health, or those that present differently in women than men, must be a priority for federally-funded research. Women's health research is a central part of the Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD)'s research mission and portfolio, and the Institute has achieved great success in advancing research on women's health throughout the life cycle; maternal, child, and family health; fetal development; reproductive biology; population health; and medical rehabilitation. With sufficient resources, NICHD can build upon its existing initiatives to produce new insights and solutions to benefit women and families. ACOG supports an appropriation of $41.6 billion for the National Institutes of Health (NIH) in fiscal year 2020, including $1.6 billion for NICHD. This amount would maintain a steady trajectory of $2.5 billion annual increases for the NIH.

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

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

ACOG also supports the request of a report on the total dollar amount of research invested in health conditions specific to women over the last 10 years, including but not limited to pregnancy, gynecologic oncology, and infertility; including information about how this research is prioritized and coordinated across the NIH.

Advancing Maternal Therapeutics at the NIH:

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

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

Family planning and pre-pregnancy care are imperative to ensuring healthy women and healthy pregnancies. The Title X Family Planning Program provides essential services to over 4 million low income men and women who may not otherwise have access to these services. For many individuals, particularly those who are low-income, uninsured or adolescents, Title X is essential to their ability to affordably and confidentially obtain birth control, cancer screenings, STI tests and other basic care. From 2010–2014, Title X funding was cut by $31 million, despite an increase in the number of patients by one million over the same period. Due to these cuts, there have been decreases in the number of patients served. ACOG requests $400 million for Title X in fiscal year 2020 to ensure individuals in need have access to evidence-based care.

ACOG is also very concerned that the Administration's March 4th final rule will dangerously undermine physicians' ability to offer patients medically accurate, comprehensive care, and urges Congress to show its strong support by not only funding this critical program but ensuring that no funds are used to implement the harmful final rule.

Title V Maternal and Child Health Block Grant at HRSA:

The Title V Maternal and Child Health (MCH) Block Grant at HRSA is the only Federal program that exclusively focuses on improving the health of mothers and children. The Block Grant is a cost-effective, accountable, and flexible funding source used to address critical, pressing, and unique needs of maternal and child health populations in each State, territory and jurisdiction. Notably, through the Special Projects of Regional and National Significance (SPRANS) discretionary grant, the Block Grant supports the Alliance for Innovation on Maternal Health (AIM)—a program that works with States and hospital systems to implement evidence-based toolkits, or bundles, to improve maternal outcomes and reduce rates of maternal mortality and severe morbidity. For fiscal year 2020, ACOG requests at least $698 million for the Block Grant to maintain its current level of services, including $5 million within SPRANS to support continued implementation of AIM.

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

AHRQ is the Federal agency with the sole purpose of improving healthcare quality. AHRQ produces data with the mission of making healthcare safer, higher quality, more accessible, equitable, and affordable. AHRQ works with HHS and other partners to ensure that the evidence improves patient safety. ACOG supports $460 million for AHRQ in fiscal year 2020, which is consistent with the fiscal year 2010 funding level for the agency adjusted for inflation.

Public Health Surveillance at CDC:

Uniform, accurate, and comprehensive data is essential for addressing the rising rates of maternal mortality and severe maternal morbidity in the United States. Unfortunately, the Nation's public health data systems are antiquated, lack interoperability and data and reporting standards, and are in dire need of security updates. There are five core data systems of the U.S. public surveillance enterprise that require modernization now to protect the health security of all Americans: (1) the National Notifiable Disease Surveillance System (NNDSS) to collect vital individual case data to assess national disease burden; (2) Electronic Case Reporting (eCR), the automatic submission of disease report from electronic health records to health departments; (3) Syndromic surveillance to provide real-time data on hospital emergency departments; (4) Electronic Vial Records systems, the secure collection of birth and death data; and (5) Laboratory Information Systems, the management and sharing of laboratory data to inform public health decisionmaking. ACOG urges Congress to show a robust investment in public health surveillance, and requests funding to be used to modernize these systems to improve American's health. ACOG requests $100 million in fiscal year 2020 and $1 billion over 10 years to support this new initiative.

Firearm Morbidity and Mortality Prevention—CDC:

In 2017, there were more than 39,000 U.S. firearm-related fatalities. federally funded public health research has a proven track record of reducing public health-related deaths, whether from motor vehicle crashes, smoking, or Sudden Infant Death Syndrome. This same approach should be applied to increasing gun safety and reducing firearm-related injuries and deaths, and CDC research will be as critical to that effort as it was to these previous public health achievements. The foundation of a public health approach is rigorous research that can accurately quantify and describe the facets of an issue and identify opportunities for reducing its related morbidity and mortality. For fiscal year 2020, ACOG requests $50 million for CDC to conduct public health research into firearm morbidity and mortality prevention.

Diagnosing and Treating Maternal Depression—HHS:

About 1 in 5 women experience maternal depression, and ACOG recommends that all women be screened, yet women face barriers to accessing treatment. ACOG commends Congress for fully funding Sec. 10005 of Public Law 114–255 in the Consolidated Appropriations Act of 2018 to establish a program at HHS to expand depression screening and treatment for pregnant and postpartum women. ACOG urges you to again fully fund the program at $5 million for fiscal year 2020.

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

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

PREPARED STATEMENT OF THE AMERICAN COLLEGE OF PHYSICIANS

The American College of Physicians (ACP) is pleased to submit the following statement for the record on its priorities, as funded under the U.S. Department of Health & Human Services, for fiscal year 2020. ACP is the largest medical specialty organization and the second-largest physician group in the United States. ACP members include 154,000 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 2020, ACP is urging funding for the following proven programs to receive appropriations from the Subcommittee:

—Title VII, Section 747, Primary Care Training and Enhancement (PCTE), Health Resources and Services Administration (HRSA), $71 million;
—National Health Service Corps (NHSC), $830 million in total program funding;
—Agency for Healthcare Research and Quality (AHRQ), $460 million;
—Centers for Medicare and Medicaid Services (CMS), Program Operations for Federal Exchanges, $690 million;
—Continue opioid crisis funding for Comprehensive Drug Addiction and Recovery Act (CARA) programs, State Targeted Response to the Opioid Crisis (Opioid STR) grant program funding, and SUPPORT Act, $3 billion;
—Centers for Disease Control and Prevention (CDC), $7.8 billion, Injury Prevention and Control, Research on Prevention of Firearms-related Injuries and Deaths, $50 million;
—National Institutes of Health (NIH), $41.6 billion.

The United States is facing a shortage of physicians in key specialties, notably in general internal medicine and family medicine—the specialties that provide primary care to most adult and adolescent patients. Current projections indicate there will be a shortage of 14,800 to 49,300 primary care physicians by 2030. (IHS Inc., prepared for the Association of American Medical Colleges. 2018 Update, The Complexities of Physician Supply and Demand: Projections from 2016 to 2030. March,

2018. Accessed at: https://aamc-black.global.ssl.fastly.net/production/media/filer__public/85/d7/85d7b689-f417-4ef0-97fb-ecc129836829/aamc__2018__workforce__projections__update__april__11__2018.pdf). Without critical funding for vital workforce programs, this physician shortage will only grow worse.

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

The College urges at least $830 million in total program funding for the NHSC. For fiscal year 2020, the NHSC's funding situation is particularly dire and faces a funding cliff because its mandatory funding is set to expire. In fiscal year 2018, the NHSC received $105 million in discretionary funding to expand and improve access to quality opioid and substance use disorder treatment in underserved areas, in addition to $310 million in mandatory funds. The Subcommittee continued the $105 million in discretionary funds in fiscal year 2019. The NHSC awards scholarships and loan repayment to healthcare professionals to help expand the country's primary care workforce and meet the healthcare needs of underserved communities across the country. In fiscal year 2018, with a field strength of over 10,900 primary care clinicians, NHSC members are providing culturally competent care to over 11.5 million patients at over 16,000 NHSC-approved healthcare sites in urban, rural, and frontier areas. These funds would help maintain NHSC's field strength helping to address the health professionals' workforce shortage and growing maldistribution. There is overwhelming interest and demand for NHSC programs, and with more funding, the NHSC could fill more primary care clinician needs. In fiscal year 2016, there were 2,275 applications for the scholarship program, yet only 205 awards were made. There were 7,203 applications for loan repayment and only 3,079 new awards. Accordingly, ACP urges the subcommittee to double the NHSC's overall program funding to $830 million to meet this need.

AHRQ is the leading public health service agency focused on healthcare quality. AHRQ's research provides the evidence-based information needed by consumers, clinicians, health plans, purchasers, and policymakers to make informed healthcare decisions. The College is dedicated to ensuring AHRQ's vital role in improving the quality of our Nation's health and recommends a budget of $460 million, restoring the agency to its fiscal year 2010 enacted level adjusted for inflation. This amount will allow AHRQ to help providers help patients by making evidence-informed decisions, to fund research that serves as the evidence engine for much of the private sector's work to keep patients safe, to make the healthcare marketplace more efficient by providing quality measures to health professionals, and, ultimately, to help transform health and healthcare. With a quarter of the agency's program level budget supported by the Patient-Centered Outcomes Research Trust Fund, a strong investment in the AHRQ appropriation will be essential to sustain the agency's core activities as the Trust Fund undergoes reauthorization this year.

ACP supports at least $690 million in discretionary funding for Federal exchanges within CMS' Program Operations, which has been funded at $2.52 billion the last several fiscal years. This funding would allow the Federal Government to continue administering the insurance marketplaces, as authorized by the Affordable Care Act, if a State has declined to establish an exchange that meets Federal requirements. CMS now manages and operates some or all marketplace activities in over 30 States. If the Subcommittee decides to deny these funds, it will be much more difficult for the Federal Government to operate and manage a federally-facilitated exchange in those States, raising questions about where and how their residents would obtain and maintain coverage.

ACP supports continuing appropriations for the CARA of 2016's grant programs, continuing the Opioid STR grant program's prior year increase, and funding the SUPPORT Act's programs in fiscal year 2020. The College urges the Subcommittee to continue the $3 billion provided for fiscal year 2018 and fiscal year 2019 in the Bipartisan Budget Act of 2018 to help expand proven programs such as evidence-based medication-assisted treatment and first-responder training and access to naloxone for overdose reversal.

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. The College also supports $50 million for the CDC's Injury and Prevention Control to fund research on prevention of firearms-related injuries and deaths and support 10 to 20 multi-year studies and help rebuild lost research capacity in this area.

Lastly, the College strongly supports $41.6 billion for NIH in fiscal year 2020 so the Nation's medical research agency continues making important discoveries that treat and cure disease to improve health and save lives and that maintain the United States' standing as the world leader in medical and biomedical research.

The College greatly appreciates the support of the Subcommittee on these issues and looks forward to working with Congress on the fiscal year 2020 appropriations process.

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

PREPARED STATEMENT OF THE AMERICAN COLLEGE OF PREVENTIVE MEDICINE

The American College of Preventive Medicine (ACPM) urges the Senate Labor, Health and Human Services, Education, and Related Agencies Appropriations Subcommittee to support training for preventive medicine physicians and other public health professionals by providing $24 million in fiscal year 2020 to the Heath Resources and Services Administration (HRSA) for the Public Health and Preventive Medicine line item in Title VII of the Public Health Service Act. ACPM also supports the recommendation of the Health Professions and Nursing Education Coalition of $690 million in fiscal year 2020 to support all health professions and nursing education and training programs authorized under Titles VII and VIII of the Public Health Service Act.

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

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

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

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

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

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

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

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

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

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

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

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

Many of the leaders of our Nation's local and State health departments are trained in preventive medicine. Their unique combination of expertise in both medical knowledge and public health makes them ideal choices to head the fight against chronic disease as well as other threats to our Nation's health, such as the opioid epidemic. Their contributions are invaluable. Investing in the residency programs that provide physicians with the training and skills to take on these leadership positions is an essential part of keeping Americans healthy and productive. As such, the American College of Preventive Medicine urges the Labor, Health and Human Services, Education, and Related Agencies Appropriations Subcommittee to reaffirm its support for training preventive medicine physicians and other public health professionals by providing $24 million in fiscal year 2020 to HRSA for the Public Health and Preventive Medicine line item in Title VII of the Public Health Service Act.

[This statement was submitted by Kate McFadyen, Senior Manager, Government Affairs, American College of Preventive Medicine.]

PREPARED STATEMENT OF THE AMERICAN COUNSELING ASSOCIATION

Dear Chairman Blunt and Ranking Member Murray:

Thank you for the opportunity to provide this written testimony on behalf of the American Counseling Association—a not-for-profit, professional and educational organization that is dedicated to the growth and enhancement of the counseling profession. We are the world's largest association exclusively representing professional counselors in various practice settings with 54,000+ members nationwide.

The Labor, HHS, Education Appropriations Bill contains several critical programs for students, families, and communities across the country. The counseling profession strongly supports prevention and by providing a sustained investment in the programs outlined below, the Federal Government can play a key role in providing treatment to our most vulnerable population—children.

The research is clear—depressed and anxious students are more likely to be absent, take semesters off, and/or drop out of school.[1] Connecting these consequences later in life is further damaging as these lost students are less likely to attain well-paying jobs and achieve productive life goals.[2] The investments that Congress supports today will impact the outcomes of our elementary, secondary, and post-secondary students throughout their lives.

The American Counseling Association offers its full support for the programs outlined below.

DEPARTMENT OF EDUCATION

Student Support and Academic Enrichment Grants—ESSA Title IV Part A

—Fiscal year 2020 American Counseling Association Supported Level—$1.6 billion
—Fiscal year 2020 President's Budget Request—$0
—Fiscal year 2019 Enacted Level—$1.17 billion

In 2015, the Every Student Succeeds Act (ESSA) eliminated the Elementary and Secondary School Counseling Program, the only direct Federal investment in school counselors. Title IV Part A established the Student Support and Academic Enrichment Grants which allocates block grants to States for local educational agencies (LEA) to apply for and implement using several allowable activities, including school counseling and mental health services. Unfortunately, Title IV Part A has not been funded to its authorized level, $1.6 billion, in the preceding fiscal years. In the fiscal year 2020 Department of Education budget proposal, it was eliminated altogether with a $0 recommendation.

We thank the subcommittee leadership for increasing the funding for these critical grants to $1.17 billion in fiscal year 2019 but the need across the country for investment in school counseling programs continues to grow. The American Counseling Association supports the fiscal year 2020 Authorized Level of $1.6 billion for the Student Support and Academic Enrichment Grants.

Mental Health Demonstration Program

—Fiscal year 2020 American Counseling Association Supported Level—$20 million
—Fiscal year 2020 President's Budget Request—$15 million
—Fiscal year 2019 Enacted Level—$10 million

In the fiscal year 2019 Labor, HHS, Education Appropriations Bill, Congress included $10 million for a Mental Health Demonstration Program to encourage innovative higher education partnerships in local school districts with an emphasis on those with the highest need. In the absence of a dedicated Federal funding stream for school counselors, the American Counseling Association strongly supported this program.

Since the demonstration was created, the Department of Education has been preparing a notice for funding which could be released in the Summer of 2019. We do not want to see this be a one-time investment in school based mental health services—continued funding for this initiative is critical to maximize the impact. As we have unfortunately seen with recent tragic suicides from family members and students connected to previous school shootings, the pain and suffering from these events does not stop. It alters the lives of the students, parents, and communities involved.

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[1] Eisenberg, Daniel. Connections between mental Health and Academic Outcomes. Ann Arbor, MI: University of Michigan, March 13, 2014.

[2] Douce, Louise A., Richard P. Keeling, American Council on Education, American Psychological Association, and Student Affairs Administrators in Higher Education. A Strategic Primer on College Student Mental Health. Rep. Washington, DC: American Council on Education, 2014.

The Administration increased funding to $15 million in its fiscal year 2020 budget proposal. We expect that the need for these investments will outpace the funding level, so the American Counseling Association supports increasing the funding for the innovative partnerships grant to $20 million in fiscal year 2020.

Public Service Loan Forgiveness (PSLF)

Licensed professional counselors often work in high pressure and low wage positions that serve the public good—either in schools or medically underserved areas, for example. The American Counseling Association thanks you for your continued support of the PSLF program by providing $700 million in loan forgiveness over the previous two fiscal years. However, we are concerned about barriers to accessing this benefit and the extremely high denial rate. A recent letter from the Department of Education stated that the program has a 96 percent denial rate. This is entirely unacceptable—the investment made in the Labor, HHS, Education Bill should serve as a strong indicator to these professionals that we support and believe in their work. Unnecessary burdens that make the funds difficult to access go against the purpose of the program. We support efforts to reform the PSLF process to make it more accessible to those serving.

DEPARTMENT OF HEALTH AND HUMAN SERVICES

Behavioral Health Workforce Development Programs—HRSA

—Fiscal year 2020 American Counseling Association Supported Level—$111,916,000

—Fiscal year 2020 President's Budget Request—$111,916,000

—Fiscal year 2019 Enacted Level—$111,916,000

The Behavioral Health Workforce Development Programs are critical to the further development and expansion of the behavioral health workforce serving populations across the country, including in rural and medically underserved areas. Opioid use and its resulting deaths have impacted the lives of individuals and families, crippled communities, and depleted limited resources.

The Behavioral Health Workforce Development Programs include the Behavioral Health Workforce Education and Training (BHWET) Program, which includes the Opioid Workforce Expansion Program (OWEP), and the Graduate Psychology Education (GPE) Program. In the 2017–2018 Academic Year, the BHWET Program supported training for 5,867 individuals—over 50 percent of these students received training in substance abuse treatment.[3] The reach of the opioid and mental health crises gripping our Nation are constrained geographically and we need a licensed, trained workforce to be able to serve as many individuals in their communities as possible. Without access to treatment, we risk losing track of those that need help the most.

The American Counseling Association supports continued funding for the Behavioral Health Workforce Development Programs at the fiscal year 2019 enacted level—$111,916,000.

Project AWARE—SAMHSA

—Fiscal year 2020 American Counseling Association Supported Level—$200,000,000

—Fiscal year 2020 President's Budget Request—$101,964,000

—Fiscal year 2019 Enacted Level—$91,916,000

Project AWARE is designed to identify children and youth in need of mental health services, increase access to mental health treatment, and promote mental health literacy among teachers and school personnel. All three of the components are critical for a comprehensive approach to address the mental health needs in schools across the country. The Administration proposed a $10 million increase in funding for this program in its fiscal year 2020 budget proposal, but the American Counseling Association supports a more robust investment. H.R. 1109, bipartisan legislation known as The Mental Health in Schools Act, would create a $200 million grant program at HHS to address school based mental health services and strategies needed train related personnel and families in serious mental health situations. The American Counseling Association strongly supports H.R. 1109 and that is the basis for our support of a $200 million investment in Project AWARE in fiscal year 2020.

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[3] Department of Health and Human Services. Fiscal year 2020 Health Resources and Services Administration. Justification of Estimates for Appropriations Committees. PP 124–126.

Suicide Lifeline—SAMHSA

—Fiscal year 2020 American Counseling Association Supported Level—$12,000,000

—Fiscal year 2020 President's Budget Request—$12,000,000

—Fiscal year 2019 Enacted Level—$12,000,000

The National Suicide Prevention Lifeline answered over 2 million calls in 2018 to provide access to crisis intervention and emergency response (when needed). SAMHSA also coordinates this Lifeline with the Department of Veterans Affairs to ensure that veterans, service members, and their families have access to the 24/7 VA's Veterans Crisis Line. $12 million in fiscal year 2020 will enable SAMHSA to continue funding two new Crisis Center follow up grant providing an integrated hub to ensure systematic follow-up of suicidal persons, enhanced coordination of crisis stabilization, and coordination with on-site crisis response personnel.[4]

Unaccompanied Alien Children—ACF

The American Counseling Association expressed its sincere concern over reports from the HHS Inspector General in 2018 which noted a shortage of mental health counselors at the Tornillo influx care facility. We urge the subcommittee to ensure that the Office of Refugee Resettlement has sufficient Federal resources to increase the number of mental health counselors in Tornillo—and around the country—so that each facility reaches the 1:12 clinician-to-child ratio required by the ORR. Providing refugee children with adequate mental health counseling is the right thing to do. And, because these children are here asking to live in America, it makes sense to help them survive the trauma of being separated from their parents and being held at an ORR influx facility.

Robust investments by your Subcommittee in these programs would greatly benefit America's students and better prepare mental health service providers in schools and communities.

Sincerely.

[This statement was submitted by Richard Yep, CAE,FASAE, Chief Executive Officer, American Counseling Association.]

PREPARED STATEMENT OF THE AMERICAN DIABETES ASSOCIATION

For fiscal year 2020, the American Diabetes Association (ADA) urges the Subcommittee to increase its investment in diabetes research and prioritize funding for diabetes prevention to help stop the diabetes epidemic in our country. This is best accomplished by the Subcommittee providing funding levels of $2.165 billion for the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) at the National Institutes of Health (NIH), $185 million for the Division of Diabetes Translation (DDT) at Centers for Disease Control and Prevention (CDC), and $30 million for the National Diabetes Prevention Program (National DPP) at CDC.

Over 30 million Americans live with diabetes and an additional 84 million Americans have prediabetes. I have spent my entire career-over three decades-working with diabetes: researching the disease, teaching and taking care of patients, and applying scientific discoveries to practice. Endocrinologists like me are one part of an important team of diabetes caregivers including nurses, nutritionists, educators, and pharmacists. Together, this team works to help patients manage diabetes so they avoid complications and lead relatively normal lives. Thanks to the medical discoveries and advancements at the NIH and translational research from the CDC diabetes care has advanced tremendously in recent years.

Although insulin was discovered nearly a century ago, we are still at the beginning of diabetes care. Newer insulins are available, providing more options than we had in 1922, but we still see the impact of the disease both in complications directly attributable to the disease—blindness, kidney disease, amputations—and in problems stemming from the stressors caused by the disease—increased depression, divorce, and suicide of people with diabetes. Our impact is not great enough, and better research into understanding and treating diabetes is the only way to reverse the troubling impact of the disease.

NIH is the single most important funding source for any researcher. As an academic physician, I have served as an investigator on several 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. Two

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[4] Department of Health and Human Services. Fiscal year 2020 Substance Abuse and Mental Health Services Administration. Justification of Estimates for Appropriations Committees. PP 64–66.

studies I have been involved with include TrialNet, which looks at agents that can prevent type 1 diabetes and halt diabetes progression by preserving insulin production early in the disease, and a Special Diabetes Program-funded (SDP) study examining unusual and atypical diabetes. NIH research provides the best hope both for those who have been living with diabetes for decades and for those who are newly diagnosed. CDC's translational role in this process cannot be understated. Federal investment in diabetes research and the translation of that research has advanced diabetes care in the decades of my practice, and continued investment is necessary.

The human cost of diabetes is significant. The lifetime risk for developing diagnosed diabetes among U.S. adults is 40 percent. Today alone, 4,110 Americans will be diagnosed with diabetes, diabetes will cause 295 Americans to undergo an amputation, and 137 will enter end-stage kidney disease treatment. In addition to the physical toll, diabetes is economically devastating to our country and individuals with the disease. Released in March 2018, "Economic Costs of Diabetes in the U.S. in 2017," found the total annual cost of diagnosed diabetes in our country has skyrocketed by an astonishing 26 percent over 5 years, to $327 billion—$237 billion in direct medical costs and an additional $90 billion in reduced productivity. This is unsustainable for our Nation, especially when 1 in 3 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 2020.

BACKGROUND

Diabetes is a chronic disease impairing the body's ability to utilize food. The hormone insulin, which is made in the pancreas, is needed for the body to convert food into energy. In people with diabetes, either the pancreas does not create insulin (type 1 diabetes), or it does not create enough insulin and/or cells are resistant to insulin (type 2 diabetes). Diabetes results in too much glucose in the blood stream. Blood glucose levels that are too high or too low (because of medication to treat diabetes) can be life threatening in the short term and cause long term complications like kidney failure, blindness, and non-traumatic lower limb amputations. Diabetes is also a leading cause of heart disease and stroke. Additionally, up to 9.2 percent of pregnancies are affected by gestational diabetes, a form of glucose intolerance diagnosed during pregnancy that places both mother and baby at risk for complications and for type 2 diabetes later in life. There are other rarer forms of diabetes, including maturity-onset diabetes of the young (MODY) and neonatal diabetes mellitus (NDM), both caused by a single gene mutation. Individuals with prediabetes have higher than normal blood glucose levels and are at risk for developing type 2 diabetes, but they can lower that risk with lifestyle interventions. Diabetes does not have a cure, and management is necessary every single day. People with diabetes make over 300 decisions about their disease in a single day. They must carefully balance what they eat, when they eat, when and how much they exercise, and insulin injections constantly, knowing that one decision impacts all of the others. 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 ADA requests funding of $2.165 billion for NIDDK in fiscal year 2020 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—but again, further research will lead to even better insulins. NIDDK research has led to the development of continuous glucose monitors and insulin pumps, which are life-changing management tools for 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 2020 funding of $2.165 billion, the NIDDK would be able to fund additional investigator-initiated research grants to meet critical needs in areas such as:

—Improving understanding of gestational diabetes, including optimal gestational age to identify gestational diabetes, best method to identify gestational diabetes, best treatment for gestational diabetes, and later impact of gestational diabetes on the health of mother and child,
—How to use and implement precision medicine in diabetes (e.g. NIH's All of Us research campaign),
—How to better prevent and treat type 1 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 to advise patients daily.

The ADA urges Congress to provide DDT with $185 million in fiscal year 2020. 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

It is alarming that 84 million Americans have prediabetes and are on the cusp of developing type 2 diabetes. I practice in a diverse area on the southside of Chicago, and we are not making enough of an impact on this neighborhood. Like many places around the country, we have a high rate of prediabetes. Programs such as the National DPP can make a significant dent in the incidence diabetes in this high-risk population. Nine of ten individuals with prediabetes do not know they have it, and 15—30 percent of individuals with prediabetes develop type 2 diabetes within 5 years. Managed by the CDC, the National DPP is a public-private partnership of community organizations, private insurers, employers, healthcare organizations, faith-based organizations, and government agencies focused on type 2 diabetes prevention.

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

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

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

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

The ADA urges Congress to provide $30 million for the National DPP in fiscal year 2020 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—specifically in hardest-hit communities, continue to manage its recognition program to ensure sites follow the evidence-based curriculum and achieve the same high level of results, and support programs as they become Medicare suppliers.

CONCLUSION

The time to invest in diabetes research, education, and prevention is now. We can and must continue to make progress; the 30.3 million Americans with diabetes cannot wait. I urge the Subcommittee to make decisions for fiscal year 2020 appropriations that reflect the necessity of reversing the human and economic burden of this staggering disease. I look forward to working with you and the ADA to stop diabetes.

[This statement was submitted by Louis H. Philipson, MD, PhD, FACP, President, Medicine & Science, American Diabetes Association.]

PREPARED STATEMENT OF THE AMERICAN EDUCATIONAL RESEARCH ASSOCIATION

Chairman Blunt, Ranking Member Murray, and Members of the Subcommittee; thank you for the opportunity to submit written testimony on behalf of the American Educational Research Association. AERA recommends that the Institute of Education Sciences (IES) within the Department of Education receive $670 million in fiscal year 2020. This recommendation is also consistent with the request from the Friends of IES coalition, in which we are a leading member. In addition, AERA recommends $1.6 billion in fiscal year 2020 for the Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD).

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

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

We see numerous examples of bipartisan support for scientific research and evidence-based decisionmaking. Last year, Congress passed the Foundations of Evidence-Based Policymaking Act, directing Federal agencies to leverage data and evaluations for informing policy decisions. States and school districts are continuing to implement the Every Student Succeeds Act, which encourages selecting evidence-based interventions that best support student needs and foster school improvement. The re-introduction in this Congress of the College Transparency Act also demonstrates a commitment to provide additional data for students seeking information on colleges, financial aid, and outcomes. These improvements to the data and research infrastructure require additional funding necessitating action by your committee.

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

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

As States are moving forward implementing their Every Student Succeeds Act (ESSA) State plans, they are increasingly depending on their Statewide Longitudinal Data Systems (SLDS). Initially developed to help States measure accountability to their students, data has transformed from a hammer to a flash light, increasing understanding about student performance and teacher effectiveness. To date, IES has been unable to meet the State demand for SLDS grants. In 2015, only 16 of 43 States that submitted applications received grants. Those States that have benefitted from SLDS grants have clear success to show from the Federal investment. State leaders in Georgia and Mississippi have testified in front of Congress about their use of SLDS to improve student outcomes in their States.

I also want to bring to your attention the numerous ways that Congress has signaled support for the use of education data in decisionmaking. The most recent bipartisan, bicameral draft of the IES reauthorization includes the continuation of SLDS. Eliminating SLDS would act in direct contrast to the broad bipartisan support to increase the use of data to inform policy decisions. Furthermore, cuts to SLDS hurt States working to build data capacity at the same time that ESSA is requiring States to make evidence-based decisions. Rather than eliminating the SLDS program, AERA encourages this committee to expand upon this very successful program. In addition, AERA opposes the proposal to eliminate the Regional Educational Laboratories in the fiscal year 2020 budget.

In addition to IES, AERA recommends $1.6 billion in fiscal year 2020 for the Eunice Kennedy Shriver NICHD, consistent with the Friends of NICHD request. Funding for NICHD supports research at the intersection of health and education, including the genetic and behavioral risks for child obesity, the use of opioids by mothers and potential impact on infant and child brain development, and interventions for students with learning disabilities who struggle with reading. This investment in NICHD will allow the institute to align resources as part of its ongoing strategic planning process, continue research to both increase understanding of the impact of opioid use across the educational lifespan and to reduce risk for addiction, and to bolster the professional development of early career researchers.

Thank you for the opportunity to submit written testimony in support of $670 million for IES and $1.6 billion for NICHD in fiscal year 2020. AERA welcomes working with you and your subcommittee on strengthening investments in essential research, data, and statistics related to education and learning.

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

PREPARED STATEMENT OF THE AMERICAN FOUNDATION FOR SUICIDE PREVENTION

My name is John H. Madigan, Jr. and I am the Senior Vice President and Chief Public Policy Officer for the American Foundation for Suicide Prevention (AFSP). I am pleased to submit this written testimony today on behalf of our almost 30,000 Field Advocates nationwide, and the thousands of individuals who participate in our Out of the Darkness Walks each year. AFSP has Chapters in all 50 States and sponsors a variety of events and programs across the country each year. In addition to raising to raising funds for research, education, and advocacy, our Chapters also disseminate resources and programs in their communities. This written testimony includes information that outlines the suicide crisis in the United States and information about each of AFSP's recommendations to the Subcommittee for fiscal year 2020.

Suicide is a major public health crisis in the United States. Suicide is the 2nd leading cause of death for ages 10–34, the 4th leading cause of death for ages 35–54, and the 10th leading cause of death overall in the United States. Every year over 10 million people seriously consider suicide, over 1 million attempt suicide, and in 2017 we lost over 47,000 Americans to suicide. Each of these individuals lost to these preventable deaths are survived by tens of thousands of family, friends, and community members. Despite such a high rate of incidence and despite nearly 1-

in-5 Americans living with a mental health condition, more than half of those individuals won't seek treatment due to poor public access to suicide prevention and treatment resources, sparse and inadequate mental health services, and deeply entrenched stigma. The most recent data from the Centers for Disease Control and Prevention (CDC) confirmed that suicide rates are rising in the United States. Suicide deaths across the country increased over 30 percent since the turn of the century and continue to do so every year.

AFSP believes Congress must prioritize suicide prevention research, programs, and education at funding levels commensurate with other leading causes of death in the United States. We thank the Subcommittee, Chairman Blunt and Ranking Member Murray for this opportunity. Please find below AFSP's recommendations on funding and report language for the Subcommittee to consider for fiscal year 2020.

Suicide Prevention Programs at SAMHSA need a greater investment towards crisis and support services for suicide prevention activities throughout the country. These programs include:

The National Suicide Prevention Lifeline (1–800–273–8255), one of SAMHSA's most effective and far reaching suicide prevention initiatives, which provides free 24/7 confidential support and resources for individuals experiencing distress, as well as prevention, education, and best practices for professionals. The Lifeline was funded at $12 million in fiscal year 2019 and the President's fiscal year 2020 budget proposes keeping the Lifeline at that same funding level. AFSP proposes an increase of $13 million, for a total of $25 million for the National Suicide Prevention Lifeline program to ensure more dedicated funding can be directed to the States with the lowest answer rates and with the highest need, and for national initiatives to better improve Lifeline quality and services.

—Fiscal Year 2019 actual: $12 million
—Fiscal Year 2020: $25 million—proposed
—Proposed Report Language: "National Suicide Prevention Hotline.—The Committee is concerned with the growing number of suicide deaths in the United States. According to data released by CDC, nearly 45,000 lives were lost to suicide in 2016. Data also shows that suicide rates went up more than 30 percent in half of the States since 1999 and that nearly every State saw a rate increase of some kind. The Committee urges SAMHSA to continue its commitment to the National Suicide Prevention Lifeline program, which plays a key role in suicide prevention. Further, the Committee requests that SAMHSA report to the Committees on Appropriations of the Senate and House within 6 months from the date of enactment on the level of funding required to meet the needs of the hotline, given the increases in the rates of suicide and suicide attempts, and increased awareness and use of the hotline."

The Garrett Lee Smith—Suicide Prevention Resource Center supports the National Action Alliance for Suicide Prevention's (Action Alliance) efforts nationwide to advance the implementation of the National Strategy for Suicide Prevention. The National Strategy for Suicide Prevention is the result of a joint effort by the Office of the U.S. Surgeon General and the Action Alliance, intended to guide suicide prevention actions in the United States over the next decade. It outlines four strategic directions with 13 goals and 60 objectives that are meant to work together synergistically to prevent suicide in the Nation.

—Fiscal Year 2019 actual: $5,988,000
—Fiscal Year 2020: $8,488,000—proposed
—Proposed Report Language: "The Committee is encouraged by the significant accomplishments achieved by the National Action Alliance for Suicide Prevention (Action Alliance), a public-private partnership to advance suicide prevention efforts in the United States. The Committee authorizes and appropriates $8.5 million for the Garrett Lee Smith (GLS) suicide prevention resource center. Of which, $2.5 million of this funding will support the Action Alliance's collective national efforts to advance implementation of the National Strategy for Suicide Prevention."

Suicide prevention research conducted at the National Institute of Mental Health (NIMH) will allow for better understanding, treatment and prevention of suicidality. NIMH has awarded grants totaling roughly $69 million over the last year on direct suicide prevention research, and while this is a step in the right direction, we believe that more can be done given the increasing rate of suicide across our country. AFSP is the largest funder for suicide prevention research outside of the Federal Government and much of what is known about suicide comes from studies that AFSP has helped sponsor. Our studies open up new areas of inquiry, and our council of scientific advisors helps set the national research agenda. We urge Congress to make a concerted, purposeful investment in suicide prevention research, and join our efforts in reversing the trend of this ever-worsening public health issue.

- —Proposed Report Language: "The Committee is increasingly concerned with the high and growing incidence of suicide across the country, and directs the National Institutes of Mental Health to increase suicide prevention research over fiscal year 2019 levels. NIMH is encouraged to utilize information and insights from the Action Alliance for Suicide Prevention and other sources when making recommendations for this vital area of research."

The Core State Violence and Injury Prevention Program (Core SVIPP) in the National Center for Injury Prevention and Control (NCIPC) at the CDC. Injuries and violence are the leading causes of death during the first four decades of life, regardless of gender, race or socioeconomic status. The inclusion of this dedicated funding through the National Center for Injury Prevention and Control would contribute in a meaningful way to suicide prevention by empowering States to implement, evaluate, and disseminate effective violence and injury prevention programs and policies.

- —Fiscal Year 2019: $6.7 million
- —Fiscal Year 2020: $16.7 million—proposed

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

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

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

PREPARED STATEMENT OF THE AMERICAN GERIATRICS SOCIETY

The American Geriatrics Society (AGS) greatly appreciates the opportunity to submit this testimony. The AGS is a non-profit organization of nearly 6,000 geriatrics healthcare professionals dedicated to improving the health, independence, and quality of life of all older Americans. As the Subcommittee works on its fiscal year 2020 Labor-HHS Appropriations Bill, we ask that you prioritize funding for the geriatrics education and training programs under Title VII of the Public Health Service (PHS) Act, and for aging research within the National Institutes of Health (NIH)/National Institute on Aging (NIA).

We are deeply disappointed with proposed cuts to geriatrics training and aging research outlined by President Trump in his budget plan for fiscal year 2020, and are concerned about what these cuts will mean for the care and health of older adults. The President's budget zeros out funding for the geriatrics training programs under Title VII, which support the Geriatrics Workforce Enhancement Program (GWEP) and the Geriatrics Academic Career Award (GACA) Program. Additionally, the budget proposal cuts $429 from the NIA which could stymie important progress on treating and preventing the health conditions older Americans face with growing frequency.

We urge you to reject this proposal, and ask that the Subcommittee consider the following funding levels for these programs in fiscal year 2020:

- —$51 million to support the Geriatrics Workforce Enhancement Program and the Geriatrics Academic Career Award Program (PHS Act Title VII, Sections 750 and 753(a))
- —An increase of $500 million over the enacted fiscal year 2019 level for aging research across the NIH, in addition to the funding allocated for Alzheimer's disease and related dementias

Sustained and enhanced Federal investments in these initiatives are essential to delivering high quality, better coordinated, and more cost effective care to older Americans, whose numbers are projected to increase dramatically in the coming years. According to the U.S. Census Bureau, the number of people age 65 and older will more than double between 2014 and 2060 to 98.2 million or 23.5 percent of the population; and those 85 and older will increase threefold to 19.7 million.[1] To ensure that our Nation is prepared to meet the unique healthcare needs of this rapidly growing population, we request that Congress provide additional investments nec-

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

essary to expand and enhance the geriatrics workforce, which is an integral component of the primary care workforce, and to foster groundbreaking medical research.

PROGRAMS TO TRAIN GERIATRICS HEALTHCARE PROFESSIONALS

Geriatrics Workforce Enhancement Program and Geriatrics Academic Career Award Program ($51 million)

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

The GWEP is currently the only Federal program designed to increase the number of providers, in a variety of disciplines, with the skills and training to care for older adults. The GWEPs educate and engage the broader frontline workforce including family caregivers and focus on opportunities to improve the quality of care delivered to older adults, particularly in underserved and rural areas. The GWEP program was launched in 2015 by HRSA with 44 3-year grants provided to awardees in 29 States. In November 2018, HRSA released a new funding opportunity and announced that they anticipate funding 47 GWEPs for 5 years starting July 1, 2019.

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

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 2020 appropriation of $51 million for the GWEPs and GACAs. This small increase in funding over fiscal year 2019 levels would help ensure that HRSA receives the funding necessary to carry these critically important programs forward. Additional funding will also allow HRSA to expand the number of GWEPs and GACAs and move towards closing the current geographic and demographic gaps in geriatrics workforce training.

RESEARCH FUNDING INITIATIVES

National Institutes of Health (additional $500 million over fiscal year 2019)

The institutes that make up the NIH and specifically the NIA lead the national scientific effort to understand the nature of aging and to extend the healthy, active years of life. As a member of the Friends of the NIA (FoNIA), a broad-based coalition of aging, disease, research, and patient groups committed to the advancement of medical research that affects millions of older Americans—the AGS urges a minimum increase of $500 million over the enacted fiscal year 2019 level in the fiscal year 2020 budget for biomedical, behavioral, and social sciences aging research efforts across the NIH. The AGS also supports an additional $350 million specific to research on Alzheimer's disease and related dementias (ADRD), resulting in an NIH-wide dementia research budget of at least $2.69 billion in fiscal year 2020.

The Federal Government spends a significant and increasing amount of funds on healthcare costs associated with age-related diseases. By 2050, for example, the number of people age 65 and older with ADRD is estimated to reach 13.8 million—more than double the number in 2019—and is projected to cost more than $1.1 trillion (in 2019 dollars).[2] Further, chronic diseases related to aging, such as diabetes, heart disease, and cancer continue to afflict 80 percent of people age 65 and older and account for more than 75 percent of Medicare and other Federal health expenditures.[3] Continued and increased Federal investments in scientific research will ensure that the NIH and NIA have the resources to conduct groundbreaking research

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[2] Alzheimer's Association. 2019 Alzheimer's Disease Facts and Figures. Alzheimers Dement 2019;15(3):321–87.

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

related to the aging process, foster the development of research and clinical scientists in aging, provide research resources, and communicate information about aging and advances in research on aging.

Additionally, the AGS supports the Ad Hoc Group on Medical Research recommendation to appropriate at least $41.6 billion in fiscal year 2020 for the NIH, including funds provided through the 21st Century Cures Act for targeted initiatives. We believe that a meaningful increase in NIH-wide funding, in combination with aging and ADRD specific increases, will be essential to sustain the research needed to make progress in addressing chronic disease, ADRD, and other diseases that disproportionately affect older people.

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

PREPARED STATEMENT OF THE AMERICAN HEART ASSOCIATION

On behalf of our 40 million volunteers and supporters, the American Heart Association (AHA) thanks Congress for its ongoing and strong commitment to the National Institutes of Health (NIH) and Centers for Disease Control and Prevention (CDC). We appreciate that Congress has repeatedly emphasized the need to focus resources on diseases that create the largest health and economic burden. We are concerned, however, that heart disease and stroke research and prevention continue to be underfunded compared to the devastating burden they inflict on Americans.

Although advances in research and prevention have produced large reductions in mortality, cardiovascular disease (CVD) stubbornly remains the leading cause of death and disability in the United States, affecting 121.5 million Americans and accounting for 1 in every 6 healthcare dollars spent. Recent data shows that nearly half (48 percent) of U.S. adults have some form of cardiovascular disease. Even more troubling, the overall decline in population mortality rates for CVD is slowing with actual increases for some groups. As our Nation's population ages, there is an urgent need for action to improve innovation in the treatment of CVD.

Currently, the NIH invests only 4 percent of its budget on heart research, 1 percent on stroke research, and a meager 2 percent on other forms of CVD research. AHA urges Congress to fund CVD in proportion to the burden of these deadly yet preventable diseases. Low research funding creates a weak pipeline for CVD and cardiometabolic drugs compared with other specialties such as oncology and central nervous system drugs. Only one new CVD drug was approved in 2017. In comparison, the development of oncology-focused drugs or biological products was nearly seven times greater than that of cardiovascular products. Placing the highest burden on our Nation's health and economy, heart disease, stroke and other forms of cardiovascular disease remain our Nation's top killer and most expensive disease, costing nearly $1 billion a day. This cost is projected to reach over $1 trillion a year by 2035. The American Heart Association calls on Congress to respond to the challenges presented by cardiovascular disease by providing robust funding for the NIH and CDC heart disease and stroke programs.

National Institutes of Health (NIH) Driver of Scientific Discovery and Economic Prosperity

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

In addition to enriching health, NIH generates a strong return on investment. In 2018, NIH supported more than 433,000 U.S. jobs and nearly $74 billion in economic activity in every State and in nearly all congressional districts. Between 2010–2016 NIH research investments led to 210 new medicines winning FDA approval and for every dollar increase in public basic research an additional $8.38 of industry research and development is stimulated. Yet, due to insufficient funding, NIH lost over 20 percent of its purchasing power since 2003, as other countries have boosted scientific investments, some by double digits. Moreover, NHLBI extramural heart research dropped 22 percent in constant dollars since 2003. This threatens to stall scientific progress and could deter young scientists from pursuing careers in research unless Congress acts now.

American Heart Association Advocates: We urge Congress to appropriate $41.6 billion to the NIH giving it a funding boost that will help restore its purchasing power and enhance heart and stroke research.

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

NHLBI research has produced declines in CVD death rates, yet, present funding is not commensurate with CVD burden, nor does it let scientists build on investments that have led to key advances. For example, a clinical trial showed a systolic blood pressure of 120 mm Hg in adults over age 50 cut heart attack, heart failure, and stroke events by almost a third and the risk of death by almost a quarter compared to the standard treatment target of 140 mm Hg. Adoption of these targets could save over 100,000 lives. Other life-saving research recently supported by NHLBI includes a study to improve postsurgical management for two common heart defects. The new practices cut the typical amount of time infants spent with a breathing tube by nearly 80 percent. In addition, NHLBI's long-running population-based cohort studies have made major contributions to understanding the causes of and prevention strategies for heart and vascular diseases. These studies continue to drive discovery by uncovering new links between CVD and brain health.

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

Stroke continues to inflict a massive burden on our Nation's long-term health and economic stability. An estimated 795,000 Americans will suffer a stroke this year, and more than 142,000 will die. Many of the 7 million survivors face grave physical, mental, and emotional distress. Stroke costs an estimated $45.5 billion in medical expenses and lost productivity annually. Projections also show that stroke's medical direct costs will more than double by 2035.

Budget increases for the BRAIN initiative, pain research, and Alzheimer's Disease and related dementias are helping to advance stroke science through collaborative efforts among several Institutes. For example, NINDs is working closely with the National Institute on Aging to support research on vascular contributions to cognitive impairment and dementia. This research is critical to helping our Nation prepare for the demands of an aging population and should be increased. Other examples of promising research include a possible link between a high sodium diet and dementia; brain injections post-stroke that could help repair salvageable brain tissue; and the identification of new and effective therapies for stroke recovery and rehabilitation.

In addition, new clinical trials will help determine if intense rehabilitation given to babies who suffer a stroke during the perinatal period improves their impaired mobility and enhances their developmental growth. Other promising work includes a study comparing mechanical clot removal versus standard medical care in stroke patients; a promising new combination drug therapy for individuals suffering from transient ischemic attack (TIA); and population-based studies that are assessing stroke risk and burden in diverse populations.

American Heart Association Advocates: We recommend that NHLBI be funded at $3.71 billion and NINDS at $2.419 billion.

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

Cardiovascular disease is largely preventable—and most preventable deaths are the result of cardiovascular conditions. Yet, risk factors such as increasing prevalence of diabetes mellitus, childhood obesity, and hypertension rates are rising. Additionally, the use of e-cigarettes that include the addictive substance nicotine, has reached an epidemic level. Despite this evidence, CVD prevention programs at the Centers for Disease Control including the Division for Heart Disease and Stroke Prevention, WISEWOMAN, and Million Hearts have been level-funded at best in the face of very promising results from these prevention initiatives.

Over the last 5 years, the Million Hearts program has implemented effective strategies that have prevented an estimated 500,000 heart attacks and strokes and is well on its way to achieving the ultimate goal of preventing a million CVD deaths by 2022. Similarly, WISEWOMAN has helped nearly 226,461 uninsured or underinsured women reduce their risk of CVD through preventive screenings that promote lasting, healthy behavior change. Between 2014–2017 the program identified nearly 4,000 previously undiagnosed women with having the condition of high blood pressure—a leading risk factor for heart attack and stroke. These prevention programs need more support to address the difficulty Americans face in modifying risk factors for CVD—particularly among the less educated, financially disadvantaged, and those living in rural areas of the United States.

American Heart Association Advocates: We join the CDC Coalition in asking for $7.8 billion for CDC. The association requests $160 million for the DHDSP to expand heart disease and stroke prevention efforts in State, local, and Tribal public health departments; enhance surveillance for stroke and sudden cardiac arrest; and support implementation research. We ask for $45.6 million to expand WISEWOMAN to all states, territories and the District of Columbia. We further recommend $5 million for Million Hearts 2022 to continue implementation of the ABCS of heart health (Aspirin when appropriate, Blood pressure control, Cholesterol management, and Smoking cessation), develop innovative scalable ways for communities and the healthcare sector to execute evidence-based prevention among high priority populations, and to continue efforts to increase the use of cardiac rehabilitation.

[This statement was submitted by Ivor J. Benjamin, M.D., President, American Heart Association.]

PREPARED STATEMENT OF THE AMERICAN INDIAN HIGHER EDUCATION CONSORTIUM

On behalf of the Nation's 37 Tribal Colleges and Universities (TCUs), which collectively are the American Indian Higher Education Consortium (AIHEC), we thank you for the opportunity to share our fiscal year 2020 funding requests. The following is a list of recommendations including Department, program, and funding requests.

Department of Education

Office of Postsecondary Education
—Strengthening Institutions HEA Title III—Part A (Sec. 316): $65,000,000 (discretionary)
—Perkins Career and Technical Education Programs (Sec. 117): $10,000,000

Department of Health and Human Services

—Administration for Children and Families/Office of Head Start
  —TCU-Head Start Partnership Program: $8,000,000 in existing funds
—Substance Abuse and Mental Health Services Administration, SAMHSA
  —TCU Centers of Excellence: $10,000,000

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

Currently, 37 TCUs operate more than 75 campuses and sites in 16 States. TCU geographic boundaries encompass 80 percent of American Indian reservations and Federal Indian trust lands. American Indian and Alaska Native TCU students represent at least 233 of the 573 federally recognized Tribes and hail from more than 30 States. Nearly 80 percent receive Federal financial aid. TCUs serve over 160,000 American Indians, Alaska Natives, and other rural residents each year through a wide variety of academic and community-based programs. Funding cuts in any amount to even one TCU program would force TCUs to scale back vital programs and services that students rely on to complete degree and certificate programs needed to succeed in their chosen career paths. Any reduction in funding will threaten TCU accreditation status and will further stretch overtaxed faculty and staff or result in cuts to faculty and staff. The following are justifications for TCU fiscal year 2020 funding requests.

U.S. DEPARTMENT OF EDUCATION

Strengthening Tribal Colleges (HEA Title III—Part A—Section 316): TCUs urge the Subcommittee to provide discretionary funding for Strengthening Tribal Colleges program (HEA Title III-Part A) at $65,000,000 in fiscal year 2020.

The Strengthening Institutions HEA Title III program for TCUs (Section 316) is specifically designed to address the critical, unmet needs of AI/AN students and their communities. Through this program, TCUs are able to provide student support services, native language preservation, basic upkeep of campus buildings and infrastructure, critical campus expansion, enterprise management systems, faculty for core courses, and other necessary elements for a quality educational experience. The Strengthening Institutions program provides formula-based aid to 35 TCUs through two funding sources: Part A discretionary funding (fiscal year 2019, $31.9 million) and Part F mandatory funding (fiscal year 2019, $28.1 million). While TCUs have received Part A (discretionary) funding since 1998, the Part F (mandatory) formula-based funding received by TCUs over the past 9 years has allowed each TCU to expand vital services truly needed for student success. The Part F (mandatory) funding was established in 2007 by the College Cost Reduction and Access Act (20 U.S.C. 1067q) and authorized through fiscal year 2019 to fund TCUs and other Minority Serving Institutions. Without Congressional action, the Part F program will expire at the end of fiscal year 2019 resulting in catastrophic losses to TCUs and their communities. In response to the expiration of the Part F program, we strongly urge the Subcommittee to fund the Strengthening Institutions HEA III Part A—TCU Program (Section 316) at $65,000,000 million. (This request for Part A funding at $65 million offsets the termination of the Part F program.)

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

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

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES PROGRAMS

Administration for Children and Families—Office of Head Start

Tribal Colleges and Universities Head Start Partnership Program: AIHEC requests $8,000,000 for the TCU-Head Start Partnership program. In 2017, 74.5 percent of Head Start teachers nationwide held a bachelor's degree as required by Federal law; but less than 42 percent of Head Start teachers met the requirement in Indian Country (Region 11), and only 70 percent of workers in Region 11 met the associate-level requirements, or were enrolled in associate programs, compared to 90 percent nationally. TCUs are the most cost-effective way for filling this inexcusable gap. From 2000 to 2007, the U.S. Department of Health and Human Services provided modest funding for the TCU-Head Start Program (42 U.S.C. 9843g) which helped TCUs build capacity in early childhood education by providing scholarships and stipends for Indian Head Start teachers and teacher's aides to enroll in TCU early childhood/elementary education programs. Before the program ended in 2007 (ironically, the same year that Congress specifically authorized the program in the reauthorization of the Head Start Act), TCUs had trained more than 400 Head Start workers and teachers, many of whom have since left for higher paying jobs in elementary schools. Today, TCUs such as Salish Kootenai College (Pablo, MT) are providing culturally based early childhood education free of charge to local Head Start professionals. Bay Mills Community College provides online education programming for $50/credit to Head Start staff nationwide. However, many Head Start programs are paying far more for other sources to provide training. With the restoration of this modestly funded program, TCUs can aid in building an early childhood education workforce to better serve the education needs of our AI/AN children.

Substance Abuse and Mental Health Services Administration (SAMHSA)

NEW Tribal College and University Centers for Excellence in Behavioral Health/Substance Abuse Prevention: AIHEC requests $10,000,000 to establish this program. The goal of the TCU Centers of Excellence program, similar to an existing SAMHSA program for HBCUs, is to grow a well-skilled and culturally competent AI/AN behavioral health workforce by developing an apprenticeship-based network of TCUs and partners from the health industry and local, Tribal, State, and regional providers. The TCU Centers of Excellence would share best practices in curriculum development, program implementation, and apprenticeships; recruit students to careers in behavioral health fields to address mental and substance use disorders; provide training that can lead to careers in the behavioral health fields; and prepare students for achieving credentials in behavioral health fields. The TCU Centers of Excellence would emphasize education, awareness, workforce training, and preparation for careers in mental and substance use treatment, prevention, and research, including addressing opioid abuse prevention, opioid use disorder treatment, serious mental illness, and suicide prevention.

National Institute of Health (NIH)—Native American Research Centers for Health (NARCH), AIHEC NARCH—TCU Behavioral Health Initiative. AIHEC requests robust funding to continue the Native American Research Centers for Health (NARCH) program.

Historical trauma is a reality affecting many of the 5.2 million AI/ANs living in this country. The answers leading to effective solutions to remedy the generational impact of historical trauma must come from within Tribal communities. TCUs are the best resource to implement essential research to find these answers. The AIHEC NARCH Behavioral Health Initiative is a 5-year project launched in 2013 to build Tribal research capacity in behavioral health through cohorts of competitively selected TCUs engaging in professional development, community-based participatory research, and research partnerships with Tribes and research institutions. Since 2013, three cohorts, a total of 14 TCUs, have participated in the initiative. Major accomplishments include the development of a 17-credit Indigenous research methodology graduate certificate, specialized training session for Tribal institutional review boards to examine the nuances of research in Indian Country, and five annual behavioral health research institutes. TCUs are beginning to help define research within their communities and train AI/AN student researchers by laying a solid foundation for tribally driven and tribally directed research that will improve the lives and well-being of Native communities.

CONCLUSION

Tribal Colleges and Universities provide access to high quality, culturally appropriate postsecondary education opportunities, including critical early childhood education and behavior health programs, for thousands of AI/AN students and their families. The modest Federal investment in TCUs has paid great dividends in terms of employment, education, and economic development. We ask you to renew your commitment to help move our students and communities toward self-sufficiency and request your full consideration of our fiscal year 2020 appropriations requests. Thank you.

PREPARED STATEMENT OF THE AMERICAN LIBRARY ASSOCIATION

The American Library Association (ALA) urges the Subcommittee to include in its fiscal year 2020 appropriations bill at least $206 million for programs under the Library Services and Technology Act (LSTA) administered by the Institute of Museum and Library Services (IMLS), and at least $29 million for the Innovative Approaches to Literacy (IAL) program under the Department of Education.

On behalf of ALA, I want to thank the Subcommittee for the opportunity to provide comments in support of these two important programs. ALA has been the trusted voice for academic, public, school, government and special libraries for more than 140 years, advocating for the profession and the library's role in advancing learning and ensuring access to information for all. Modest investments in both the LSTA and IAL programs are critical to achieving our mission.

LSTA is the only source of dedicated Federal funding for the more than 120,000 libraries across the Nation. The LSTA Grants to States program ensures that every State has access to needed library and information resources and the power to determine how to use them. LSTA funding of at least $206 million will support libraries in every State.

If you haven't been to a library recently, we urge you to visit your local library and see for yourself the range of services they provide your constituents, including early learning and literacy support, jobs and career development, small business assistance, access to government information, and building Internet and computing skills. Libraries also support people with print disabilities by providing content that is accessible in both print and digital forms.

The bulk of LSTA funds are distributed to each State through the IMLS according to a population-based grant formula. Each State must provide a 34 percent match and determines at the State level how to meet local needs and best allocate its LSTA grant awards. Libraries have used LSTA funding for a broad range of diverse and innovative programs that profoundly touch and better the lives of tens of millions of Americans in every State in the Nation, including particularly service to people with disabilities, veterans, and job seekers. LSTA is truly a local decision-making 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.

Lawmakers agree. Garnering bipartisan and bicameral support, the Museum and Library Services Act to reauthorize IMLS until fiscal year 2025 was signed into law in December 2018. In the 2018 reauthorization, Congress strengthened LSTA to support data-driven tools to tailor services to local needs; help libraries prepare for and provide services after a disaster or emergency; improve services for Native Americans; and recruit and train library and information science professionals from a broad range of backgrounds. The new law also enables increases in the Grants to States program to be shared more broadly across States, while ensuring no State loses funding. Given this strong congressional backing, ALA supports these newly authorized changes to the Grants to States program, which required an additional $17 million to implement the new formula included in the LSTA reauthorization.

Here are just a few current examples among many thousands made possible by LSTA over time:

—The Missouri State Library used LSTA funds to support makerspace programs. The Nevada, MO, library received a grant for its Next Level Makerspace for patrons aged 12—19. This program teaches teens to produce audio and video projects, create with textiles, experiment with technology and circuitry, and explore culinary creations, and build projects in its Engineer Zone.

—Washington State Library directed an LSTA grant to the Washington State Penitentiary Library—West Complex to serve inmate-populations. The grant supports delivery of information services to inmates, including material for reentry, recovery, education and recreation. The grant provides resources for inmates to make positive changes in their lives.

—The Rhode Island Talking Books Library makes it possible for residents who are blind, visually impaired or physically disabled to receive library materials in accessible formats for free. The State provides services as a regional library for the blind and physically handicapped, coordinating access to and delivery of reading materials for people who are not able to read traditional print material.

—The Oklahoma Department of Libraries procured access to a powerful suite of databases on business, health, and education which are available to all public State libraries. Oklahomans performed more than 50 million information searches on these databases.

—California public libraries, in partnership with California Department of Veterans Affairs, are working to connect veterans and their families to benefits and services for which they are eligible. Libraries can positively impact the quality of life for veterans.

Libraries are essential to America's communities, and the services they offer provide economic opportunity and make individual success within everyone's reach. The direct beneficiaries of the LSTA Grants to States program administered by IMLS include veterans, entrepreneurs, job seekers, taxpayers, children, and many others throughout our Nation. In addition, thanks to LSTA and other IMLS funds, many State libraries can support Libraries for the Blind and Physically Handicapped or Talking Book services, which provide access to reading materials in alternate formats. There is no dedicated Federal funding stream for these individuals at the local and State level. LSTA Grants to States funding often fills this need.

ALA respectfully submits that there can be few, if any, more democratic, cost-effective and impactful uses of Federal dollars than LSTA in the entirety of the Federal budget. The unfortunate truth is that the administration'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, ALA asks that the Subcommittee provide at least $206 million for LSTA in fiscal year 2020 to ensure that Americans of all ages continue to have access to important resources at their local library.

In addition to supporting LSTA, ALA also asks that you maintain the modest, but critical Federal investment of $29 million in the Innovative Approaches to Literacy (IAL) program. Authorized under the Every Student Succeeds Act, IAL provides competitive awards to school libraries and national not-for-profit organizations. including partnerships that reach families outside of local educational agencies, to put books into the hands of children and their families in high-need communities.

Studies have shown that early childhood learning is directly correlated to success in K–12 and college education and in careers. For families living in poverty, access to reading materials is severely limited, which hinders their ability to prepare for school and to stay on track. IAL helps bridge that gap. IAL 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 Lane Elementary School (OK), Shelby County Board of Education (TN), New Visions Middle School (CA), and Jefferson Davis County School District (MS), as well as many others.

Providing books for children with meager opportunity is crucial to their learning to read, which is crucial to their—and the Nation's—economic futures. Accordingly, we urge the Subcommittee to invest in literacy by continuing to provide at least $29 million for IAL.

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

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

PREPARED STATEMENT OF THE AMERICAN LIVER FOUNDATION

SUMMARY OF FISCAL YEAR 2020 APPROPRIATIONS RECOMMENDATIONS

—Please provide the National Institutes of Health (NIH) with a funding increase of at least $2.5 billion for fiscal year 2020 to bring total agency funding up to a minimum of $41.6 billion annually.

—Please provide proportional increases for NIH Institutes and Centers, including the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) and the National Institute of Allergy and Infectious Diseases (NIAID), which lead key research portfolios

—Please provide the Centers for Disease Control and Prevention (CDC) with a funding increase of at least $500 million in discretionary resources to bring total agency funding up to a minimum of $7.8 billion annually.

—Please provide at least $250,000 in programmatic funding to initiate a new liver cancer awareness and education effort at CDC's National Center for Chronic Disease Prevention and Health Promotion.

—Please provide between $40 million (the authorized funding level) and $58 million (the administration's requested level) for the CDC's new Elimination Initiative focused on the nexus of the opioid epidemic and the spike in infectious diseases.

—Please provide a meaningful fiscal year 2020 funding increase of $11 million for the Division of Viral Hepatitis (DVH) at the National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention, to bring total funding up to $50 million annually.

—Please provide the Health Resources and Services Administration (HRSA) with a funding increase to at least $8.56 billion for fiscal year 2020.

—Please continue to support and encourage efforts to improve organ donation and otherwise enhance the ability of donor livers for individuals waiting on the transplant list for a donated liver.

Thank you for the opportunity to submit testimony on behalf of the American Liver Foundation (ALF) and the liver disease community. Before we look forward to fiscal year 2020, we extend our thanks for the significant investments in HHS, particularly NIH, provided for fiscal year 2019. Please maintain this commitment and further enhance this support for medical research and public health programs during the fiscal year 2020 appropriations process. On behalf of the community, thank you again for this ongoing support.

ABOUT THE FOUNDATION

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

LIVER FACTS

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

LIVER CANCER PUBLIC HEALTH AT CDC

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

ORGAN DONATION

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

THE OPIOID EPIDEMIC

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

COMMUNITY STORIES

Our son Andrew was born September 30, 2013 with a genetic liver disease called Alagille Syndrome. At 8 days old we started seeing a liver specialist at Children’s of Alabama. The first year was hard as we did bloodwork several times a month trying to find a correct diagnosis. When Andrew turned a year old we finally got the diagnosis of Alagille Syndrome. The next 2 years would consist of lab work and hospital stays. Andrew was officially listed for liver transplant in June of 2017. On May 17, 2018 Andrew received his new liver! He was able to come home on June 4th. Since then Andrew has done exceptionally well with only one hospital stay. We still do monthly labs to keep a check on his levels. He is in preschool and will be starting Kindergarten this fall.

* * *

I never thought I would hear the words... “you have liver cancer″

I felt healthy. I was training for a half marathon. I had a lot of things to do. How could this be?

So, when a little shadow showed up on my liver during a test for something else, it really seemed like nothing to worry about. After all, I was 51 years old and—as far as I knew— I didn’t have liver disease.

But, I wanted to be sure so I had more tests. Before I knew it, I was one of the tens of thousands of Americans who are diagnosed with liver cancer each year.

The numbers for liver cancer are startling: In the U.S., liver cancer rates have more than tripled since 1980 (while other cancers have declined). Worldwide, liver cancer is the second leading cause of cancer-related deaths.

An early diagnosis, medical breakthroughs and great doctors saved my life!

Today, I am asking you to open your heart and help save others. If we all do our part, we can defeat liver disease.

* * *

My name is Mary. I am a wife, mom, jewelry designer, lover of books, baking, health, fitness, laughter, music and dance. Exploring the world by traveling near and far and experiencing culture through food, art, language and music are some of the things I am passionate about! My wonderfully large, supportive, loving family and friends bring huge delight to my life!

Thirty-four years ago, I had a blood transfusion during treatment for Leukemia. It saved my life but also gave me Hepatitis C. After years of trying many different forms of treatment, each with unsuccessful results, my dream of being Hep C free has come true! The arrival of new "miracle" medicine has brought me my long awaited cure! I am elated and joyful!

Living with Hep C and the deep layers of fears, uncertainties and loneliness that came with it, I experienced so many misconceptions about the disease. This has made me acutely aware and passionate for the need to educate, to share awareness and understanding within our communities and beyond.

I look forward to the day when Hepatitis C will be eradicated and we will have a chance to live a life with the hope of a future filled with many healthy years.

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

PREPARED STATEMENT OF THE AMERICAN LUNG ASSOCIATION

The American Lung Association is pleased to submit its recommendations for fiscal year 2020 to the Labor, Health and Human Services, and Education Appropriations Subcommittee.

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

IMPROVING PUBLIC HEALTH AND MAINTAINING OUR INVESTMENT IN MEDICAL RESEARCH

The American Lung Association strongly supports an increase in funding to $41.6 billion for the National Institute of Health (NIH). We need sustained investments in NIH so that the promise of biomedical research can be achieved. The Lung Association supports robust funding increases for the individual institutes within NIH, recognizing the need for research funding increases to ensure the pace of research is maintained across NIH.

LUNG DISEASE

Lung disease is the third highest killer in America, taking the lives of almost 414,000 Americans each year. It has been estimated that more than 35 million Americans suffer from a chronic lung disease and lung disease costs the economy $129 billion each year.

THE PREVENTION AND PUBLIC HEALTH FUND

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

LUNG CANCER

Lung cancer is the number one cancer killer of both women and men. It is estimated that 228,150 new cases of lung cancer will be diagnosed in 2019, and more than 158,000 Americans will die from the disease in 2016—85,920 men and 72,960 women. Survival rates for lung cancer tend to be lower than those of other leading cancers, due to the lack of early detection and diagnosis. African Americans are more likely to die from lung cancer than persons of any other racial group. We ask the Committee to increase funding for the National Institutes of Health to $41.6 billion in fiscal year 2020 and to include increased funding for lung cancer research as well as support for the Cancer Moonshoot and the All of Us Program.

TOBACCO USE

The use of tobacco is the number one preventable cause of death in the United States. More than 34 million American adults smoke and approximately half a million people die of tobacco-related disease each year. Annual healthcare and lost productivity cost more than $300 billion in the U.S. each year. Each day, about 2,000 kids under 18 years of age try their first cigarette and more than 300 kids become new, regular daily smokers. Additionally, Surgeon General Jerome Adams has declared an epidemic of e-cigarette use among youth after high school e-cigarette use increase by 78 percent in 1 year.

The CDC Office on Smoking and Health (OSH) must continue to receive robust funding to help combat the tobacco-caused diseases that are burdening the Nation. Public health interventions have been scientifically proven to reduce tobacco use, the leading cause of preventable death in the United States. The American Lung Association urges that $310 million be appropriated to OSH for fiscal year 2020.

The American Lung Association respectfully requests the Committee's support for the Office of Smoking and Health and the "Tips from Former Smokers" Campaign. Over the past 5 years, hundreds of thousands of Americans have successfully quit smoking because of "Tips" and millions more have made quit attempts. The "Tips" campaign has been an incredible return on investment that continues to generate positive outcomes. An accepted threshold for cost-effective public health interventions is approximately $50,000. The 2012 Tips campaign spent $480 per smoker who quit and $393 per year of life saved.

ASTHMA

The American Lung Association asks that you appropriate $34 million to CDC's National Asthma Control Program (NACP) in fiscal year 2020. The NACP tracks asthma prevalence, promotes asthma control and prevention and builds capacity in State programs. This program has been highly effective: the rate of asthma has increased, yet asthma mortality and morbidity rates have decreased. Currently, only 24 States receive funding—leaving a nationwide public health void that can lead to unnecessary asthma-related attacks and healthcare costs. Increased funding could help develop asthma programs in the remaining 26 States and the District of Columbia.

Additionally, we recognize the importance of robust and sustained increases for the National Heart, Lung and Blood Institute, the National Institute of Allergy and Infectious Diseases and the National Institute for Environmental Health Sciences. With increased support, these agencies will be able to continue their investments in asthma research in pursuit of treatments and cures.

CHRONIC OBSTRUCTIVE PULMONARY DISEASE

COPD (Chronic Obstructive Pulmonary Disease) is the fourth leading cause of death in the U.S. More than 18 million U.S adults had evidence of impaired lung function, indicating an under diagnosis of COPD. In 2016, 151,078 people in the U.S. died of COPD, representing one COPD death every 3.5 minutes. The American Lung Association also asks the Committee to continue its support of the National Heart, Lung and Blood Institute working with CDC and other appropriate agencies to act on its national action plan to address COPD, which should include public awareness and surveillance activities. The American Lung Association requests sustained and robust funding for the National Heart, Lung and Blood Institute as well as funding for CDC to implement the National COPD Action Plan.

The American Lung Association is requesting a new $3 million program specifically for public health activities focused on COPD at CDC through the fiscal year 2020 LHHS Appropriations Bill. In its appropriations bill, the House Appropriations Committee on Labor, Health and Human Services, Education and Related Agencies Subcommittee included funding for a new chronic disease program with specific mention of a COPD focus.

IMPACT OF CLIMATE CHANGE ON LUNG HEALTH

CDC's Climate and Health Program is the only HHS program devoted to identifying the risks and developing effective responses to the health impacts of climate change, including worsening air pollution; diseases that emerge in new areas; stronger and longer heat waves; and more frequent and severe droughts, and provides guidance to States in adaptation. Pilot projects in 16 States and two city health departments use CDC's Building Resilience Against Climate Effects (BRACE) framework to develop and implement health adaptation plans and address gaps in critical public health functions and services. As climate-related challenges intensify, CDC must have increased resources to support States and cities in meeting the challenge. The Lung Association supports $15 million for the Centers for Disease Control and Prevention's Climate and Health Program.

TUBERCULOSIS

TB (Tuberculosis), an airborne infectious disease, is a leading global infectious killer, causing 1.3 million deaths annually. In the U.S., every State reports cases of TB annually, with California, Texas, Hawaii and Alaska having the highest burdens. TB outbreaks continue to occur across the country in schools, workplaces and prisons, costing the U.S. over $460 million annually. Drug-resistant TB poses a particular challenge to TB control due to the high costs of treatment and intensive healthcare resources required. Treatment costs for multidrug-resistant (MDR) TB range from $100,000 to $300,000 per case and can be over $1 million for treatment of extensively drug resistant (XDR) TB, which can outstrip State and local public health department budgets. We request that Congress increase funding for tuberculosis programs at CDC to $243 million for fiscal year 2020.

CONCLUSION

Lung disease remains a growing problem in the United States and is leading the Nation as the third highest killer. There have been advancements in technology and medications; however, progress against lung disease has been overshadowed by developments against other major causes of death in the U.S. The level of support this committee approves for lung disease programs should be reflective of the urgency and magnitude of impact that lung disease has had on Americans.

The American Lung Association respectively requests that the Committee supports funding requests and strongly encourages you to oppose all policy riders on appropriations bills. Policy riders can weaken key lung health protections, including those in the Clean Air Act and the Tobacco Control Act. The Lung Association is appreciative of your support and we thank you for your consideration of our recommendations.

[This statement was submitted by Harold P. Wimmer, National President and CEO, American Lung Association.]

PREPARED STATEMENT OF THE AMERICAN NATIONAL RED CROSS

Chairman Roy Blunt, Ranking Member Patty Murray, and Members of the Subcommittee, the American Red Cross appreciates 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 recognizes the leadership that Congress has shown in funding CDC for these essential and life-saving activities. We request this subcommittee preserve CDC's global measles control activities for fiscal year 2020 at $50 million, as part of $226 million for the overall Global Immunization Programs line. From 2000 to 2017, an estimated 21.1 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 2000–2017, measles vaccines were the single greatest contribution to reducing preventable child deaths.

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 nearly three billion individuals in 88 countries since 2001 and saving the lives of more than 21.1 million children. In part due to the Measles & Rubella Initiative, global measles mortality has dropped 80 percent, from an estimated 545,000 deaths in 2000 to an approximately 110,000 in 2017 (the latest year for which data is available), mostly children under the age of five. During this same period, measles deaths in Africa fell by 86 percent. However, in 2017 approximately 300 children died every day from a virus that can be prevented by a safe, effective and inexpensive vaccine—generally, less than $2 USD in lower income countries. Measles is among the most contagious diseases ever known, and a top killer of children in low-income countries where children have little or no access to medical treatment and are often malnourished.

Measles spreads much more quickly than the flu or the Ebola virus. A single person infected with measles can infect up to 18 other unvaccinated people, compared with three for Ebola. The 2014–2015 Ebola outbreak in Guinea, Sierra Leone and Liberia killed a total of 11,310 people. By comparison 2014, measles killed nearly 115,000 people worldwide, more than 10 times the number of deaths from Ebola. Measles can also cause severe complications such as pneumonia and encephalitis. In addition, each year more than 100,000 children are born with congenital rubella syndrome (CRS). CRS is the leading vaccine preventable cause of severe birth defects worldwide. These birth defects can include blindness, deafness, heart defects and mental retardation. CRS is very costly to treat, yet very inexpensive to prevent. Working closely with host governments, the Measles & Rubella Initiative has been the main international supporter of mass measles immunization campaigns since 2001. The Initiative mobilized more than $1.2 billion and provided technical support in 88 developing countries on vaccination campaigns, surveillance and improving routine immunization services.

The majority of measles vaccination campaigns have been able to reach more than 90 percent of their target populations. Countries recognize the opportunity that measles vaccination campaigns provide in accessing mothers and young children and integrating the campaigns with other life-saving health interventions has become the norm. In addition to measles vaccine, other health interventions are often distributed during campaigns. These include: administering vitamin A, which is crucial for preventing blindness in under nourished children; de-worming medicine to reduce malnutrition; and distributing insecticide treated bed nets to help prevent malaria and screening for malnutrition. Doses of oral polio vaccines are also frequently dispensed during measles campaigns in polio-endemic and high-risk countries. The delivery of polio vaccines in conjunction with measles vaccines in these campaigns strengthens the reach of elimination and eradication efforts of both diseases. The provision of multiple child health interventions during a single campaign is far less expensive than delivering the interventions separately. This strategy increases the potential positive impact on children's health from a single campaign while serving to increase vaccination coverage rates.

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

Securing sufficient funding for measles and rubella-control activities both globally and nationally is critical. Between 2018–2020 the Measles & Rubella Initiative is facing a funding shortfall of US $71 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.

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

Controlling measles and rubella cases in other countries also protects adults and children in the U.S. In the United States, measles control measures have been strengthened, and endemic transmission of measles cases has been eliminated since 2000 and rubella in 2002. However, importations of measles cases into this country continue to occur each year. Since 2000, the annual number of people reported to have measles ranged from 37 in 2004 to 667 people across 27 States in 2014. Additionally, on July 2, 2015, the Washington State Department of Health confirmed a measles-related death—the first death in 12 years in the U.S. Last year, 372 people in 26 States were reported to have measles. From January 1 to May 31, 2019, 981 individual measles cases have been confirmed in 26 States, the largest number of cases since 1992.

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, 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 21.1 million children. In 2017, 205 million children were vaccinated against these diseases. For this support, we extend our deep appreciation to Congress. This support permitted the provision of technical support to Ministries of Health that specifically included: (1) planning, monitoring, and evaluating large-scale measles vaccination campaigns; (2) conducting epidemiological investigations and laboratory surveillance of measles outbreaks; (3) CDC's Global Measles Reference Laboratory to serve as the leading worldwide reference laboratory for measles and rubella. The reference laboratory provides specimen confirmation and testing as well as training for country and regional labs; and (4) conducting operations research to guide cost-effective and high-quality measles control programs.

In addition, CDC epidemiologists and public health specialists have worked closely with 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 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 2020, the American Red Cross respectfully requests the continuation of level funding of $50 million. This investment will allow CDC to maintain measles and rubella control and elimination activities, safeguard the progress made over the last decade and protect Americans by preventing measles cases and deaths in the United States. The overall CDC Global Immunization Program, through which the Measles and Rubella Initiative is funded, has been highly successful and we support full funding for the overall account. All of the programs funded through the Global Immunization Program line help to build stronger health systems. We respectfully request $50 million for CDC measles elimination activities, as part of level funding of $226 million for the entire Global Immunization account in fiscal year 2020.

Thank you for the opportunity to submit testimony, and for your continued commitment to ending preventable death and disability from measles and rubella.

[This statement was submitted by Koby J. Langley, Senior Vice President, International Services and service to the Armed Forces, American National Red Cross.]

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 2019, following on those provided in fiscal year 2016–2018 have helped NIH address critical health problems and emerging challenges through cutting-edge research. These much-needed increases have put the NIH on a path toward sustainable budget growth. The APS urges you to sustain this vital effort by providing the NIH with at least $41.6 billion in fiscal year 2020.

Breakthroughs in basic and translational research are the foundation for new drugs and therapies that help patients, fuel our economy, and provide jobs. Federal investment in research is essential because the NIH is the primary funding source for this discovery research through its competitive grants program. The private sector commercializes new treatments, but it depends upon federally-funded discovery research to point way to where the next breakthrough is likely to be found. This system of public-private partnership has been critical to U.S. leadership in the biomedical sciences. According to a recent article in the Proceedings of the National Academy of Sciences, all 210 new molecular entities approved by the Food and Drug Administration between 2010 and 2016 were associated with NIH-supported research. Importantly, 84 of those new drugs involved a newly-discovered mechanism of action or biological target in the body.[1]

Federal research dollars also have a significant impact at the local level: Approximately 83 percent of NIH's budget goes to some 30,000 researchers working in colleges, universities, and medical centers across the country. They in turn use their NIH grant funds to train students, pay research and administrative staff, purchase supplies and equipment, and cover other costs associated with their research. According to an updated 2019 report, NIH research funding in fiscal year 2018 supported more than 430,000 jobs and generated nearly $74 billion in total economic activity nationwide.[2]

The increases Congress has provided NIH over the last 4 years are helping to correct the devastating effects of sequestration and budgets that declined in real terms due to the effects of inflation. To keep the agency on a strong path forward, we urge you to provide meaningful and predictable annual budget increases that keep up with the rate of inflation and take full advantage of the incredible opportunities for discovery before us.

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

Over the past several decades, NIH has used a merit-based peer review system to identify and fund the best research proposals. To date, NIH has supported the work of 156 Nobel Laureates, including the 2018 winners of the Chemistry and Physiology or Medicine prizes. Thanks to NIH research, Americans can expect to live longer and healthier lives. NIH also plays an important role in training the next generation of scientists by supporting trainees with individual fellowships and institutional grants as they complete their graduate degrees and seek the post-doctoral training necessary to pursue successful independent research careers.

Today significant challenges loom before us: The opioid epidemic has become a national public health crisis. An aging population will bring an increase in diseases that contribute to death and disability such as heart disease, diabetes, kidney dis-

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[1] http://www.pnas.org/content/early/2018/02/06/1715368115.

[2] http://www.unitedformedicalresearch.com/wp-content/uploads/2019/03/NIHs-Role-in-Sustaining-the-US-Economy-2019-Update-FINAL.pdf.

ease, arthritis, and cancer. New and emerging infectious diseases will require us to be nimble in investing our resources. If we are to continue to advance new and innovative ways to address these and other challenges on the horizon—including developing the workforce necessary to do so—the NIH will need stable and predictable funding increases in future years.

The APS joins the Federation of American Societies for Experimental Biology (FASEB) in urging that NIH be provided with no less than $41.6 billion in fiscal year 2020. This represents a $2.5 billion increase over fiscal year 2019.

The APS is a nonprofit devoted to fostering education, scientific research and dissemination of information in the physiological sciences. The Society was founded in 1887 with 28 members and now has over 10,000 members, most of whom hold doctoral degrees in physiology, medicine and/or other health professions.

PREPARED STATEMENT OF THE AMERICAN PSYCHOLOGICAL ASSOCIATION

APA is the largest scientific and professional organization representing psychology in the U.S., numbering over 118,400 researchers, educators, clinicians, consultants and students. Many programs in the Labor-HHS-Education bill strengthen the public health workforce and support research, education, and needed services for the diverse populations served by psychologists.

Science.—To increase knowledge to advance health and education, APA supports strong investments in the Institute of Education Sciences (IES), National Institutes of Health (NIH), and Agency for Healthcare Research and Quality (AHRQ). For IES, which helps develop the research base for and evaluates the effectiveness of U.S. education programs, we request $670 million, a restoration of the nearly 10 percent decrease in purchasing power in real dollars that IES has experienced since fiscal year 2011. The additional funding would help support IES's Research, Development and Dissemination efforts. APA thanks Congress for the fiscal year 2018 and 2019 increases to the NIH accounts which have boosted the average grant success rate to about 1 in 5. But not all programs in NIH have benefited from those increases. APA asks the Committee to encourage NIH to raise from $27 million to $28 million the funding for the Office of Behavioral and Social Sciences Research (OBSSR), which coordinates and helps institutes share resources to support this critical research.

We also ask the Committee to encourage The Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD) to maintain its founding focus on human development and take a more integrated approach to understanding cognitive, behavioral, emotional, social, and environmental processes, in addition to biological and genetic processes, that affect human development. APA recommends that NIH expand its Loan Repayment Program beyond the five currently eligible extramural programmatic areas to include mission-oriented pain and addiction research. The opioid crisis requires that NIH emphasize the training of scientists in these inextricably linked research domains as well as spotlight nonhuman animal pain and addiction research.

APA opposes the Administration's proposal to move AHRQ into NIH and supports increased funding to $460 million to maintain its critical mission: advancing research to help determine how to deliver the highest quality healthcare at the greatest value and make the healthcare system safer and more efficient.

Workforce and Access to Healthcare.—To strengthen the public health workforce and improve access to healthcare, APA supports enhanced budgets for targeted programs in the Health Resources and Services Administration (HRSA) and the Substance Abuse and Mental Health Services Administration (SAMHSA). The Nation's mental and behavioral health workforce must be expanded to respond adequately to the opioid epidemic, and 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 where mental and behavioral disorders are a significant health concern.

APA appreciates the current attention to maternal mental health and maternal health disparities, and requests that the committee include report language similar to the House LHHS report requiring HHS to conduct an interagency report on maternal mental health, with additional language regarding access to care for underserved populations including people with disabilities and racial and ethnic minorities.

HRSA projects a shortage of 14,300 psychologists by 2030 to address the growing needs for behavioral interventions. APA recommends robust investments in the Bureau of Health Workforce, which supports critical interprofessional behavioral health workforce training programs. Specifically, APA strongly encourages the Committee to maintain level funding of $18 million for the Graduate Psychology Education Program, to increase the number of health service psychologists trained to provide integrated services to high-need, underserved populations in rural and urban communities. In addition, APA recommends $93.9 million for the Behavioral Health Workforce Education and Training and Opioid Workforce Enhancement Programs. To further expand access to evidence-based substance use disorder treatment in underserved communities, APA recommends initial funding of $25 million for the Substance Use Disorder Loan Repayment Program authorized in the SUPPORT Act of 2018.

As the number of Americans over age 65 will likely double between 2000 and 2030, APA further recommends $51 million for the Geriatric Workforce Enhancement Program and Geriatric Academic Career Awards to provide training for health professionals, faculty, family caregivers, and consumers in the unique needs of older adults.

Also, in HRSA, APA supports level funding for the Maternal and Child Health Block Grant and strongly recommends continued funding of $5 million to support depression screening and treatment for pregnant women. APA supports $400 million for the Title X Family Planning Program, the sole source of Federal funding for family planning for underserved populations, providing access to reproductive health services for those who may otherwise not have access.

At SAMHSA, APA urges an increase to $14.7 million for the Minority Fellowship Program. Ethnic minorities represent 30 percent of the U.S. population, but only 23 percent of recent doctorates in psychology. APA recommends $63.9 million level funding for the National Child Traumatic Stress Network, to ensure access to high quality and evidence-based behavioral health services for children in need. APA requests an additional $35 million for the Community Mental Health Services Block Grant, to fund a 5 percent set-aside for States to fund crisis care services. These funds would enable States to implement the Crisis Now strategies recommended by the National Action Alliance for Suicide Prevention, shown to be highly effective in improving care and reducing costs. The array of crisis care services for which funding would be available to States would include centrally deployed 24/7 mobile crisis units, short-term residential crisis stabilization beds, evidence-based protocols for delivering services to individuals with suicide risk, and/or regional or statewide crisis call centers coordinating in real time. Resources through the set-aside would be in addition to $80 million in fiscal year 20 funding for the National Suicide Prevention Lifeline, a fundamental part of the crisis services continuum.

APA also supports maintaining current funding for the Garrett Lee Smith Memorial Act (GLSMA) programs, which increase young adults' access to prevention, education, and outreach services to reduce suicide risk in States, Tribes, and institutions of higher education: $35.4 million for the State and Tribal Youth Suicide Prevention Program, $7 million for the Campus Mental and Behavioral Health Program, and $6 million for the Suicide Prevention Resource Center. We also recommend at least $444 million for the Substance Abuse Prevention and Treatment (SAPT) block grant, to restore purchasing power to 2009 levels. SAPT funding has not kept pace with inflation, despite the emergence of the opioid epidemic. It is a key source of funding especially for prevention activities.

Other Programs Enhancing Access to Care or Workforce Development.—APA also supports SAMHSA's Minority AIDS Initiative, providing for evidence-based, culturally appropriate, HIV/AIDS-related mental health and substance use disorder treatment services among vulnerable populations. We recommend $160m to expand efforts to prevent domestic HIV transmission and to increase treatment options for those living with co-morbid HIV, mental health and substance use conditions.

Public Health Services and Infrastructure.—APA recommends increases in funding for several CDC programs: a topline appropriation of $7.8 billion; $700 million for the CDC Injury Center to expand the evidence base for injury and violence prevention programs; $23.5 million to maintain the expansion of the National Violent Death Reporting System; $50 million for Gun Violence Prevention research on firearm morbidity and mortality prevention; and $50 million for the Division of Adolescent and School Health safe and supportive school environment programs.

To fill key gaps in education services, given the heavy burden of student loan debt, APA supports added investments in grant programs supporting graduate study, including at least $23 million for the Graduate Assistance in Areas of National Need (GAANN) Program, where psychology has been recognized as a national need area. We urge continued appropriations for the Temporary Expanded Public Service Loan Forgiveness (TE–PSLF) program to raise awareness and educate student borrowers about their eligibility as they begin careers in public and non-profit sectors. Until the Department addresses concerns with the implementation and management of the PSLF, the TE–PSLF program provides needed resources to support students who have received incorrect information that has consequently jeopardized their eligibility for the program. To ensure that our students receive a well-rounded education, and access to mental health counseling and programs that foster safe and healthy schools, we request $1.6 billion for the Student Support and Academic Enrichment (SSAE) block grant under Title IV–A.

To improve the social safety net, APA supports $1.7 billion for the Social Services Block Grant, to provide vital social services (e.g. protective services, special services to people with disabilities). To prevent child abuse and neglect, reduce the need for foster care placement, and provide the most vulnerable families the services and support they need, we support an increase in funding for the Child Abuse Prevention and Treatment Act (CAPTA): $270 million for Title I and $270 million for Title II, as well as $60 million to support safe care plans for infants with prenatal substance exposure and families impacted by substance use disorders. APA also requests $10.3 billion for the Child Care Development Fund, to expand access to safe, affordable childcare for working families.

PREPARED STATEMENT OF THE AMERICAN PUBLIC HEALTH ASSOCIATION

APHA is a diverse community of public health professionals that champions the health of all people and communities. We are pleased to submit our request for the Centers for Disease Control and Prevention and for the Health Resources and Services Administration in fiscal year 2020. We are extremely pleased with the nearly $8.3 billion provided to CDC in the House Labor, Health and Human Services, and Education, and Related Agencies Appropriations bill. This total includes a transfer of $225 million from the HHS Nonrecurring Expenses Fund for one-time projects to improve CDC campus infrastructure. We urge the Senate to match the House funding level for CDC as you develop the Senate's fiscal year 2020 Labor, Health and Human Services, and Education, and Related Agencies Appropriations bill. We also urge you to support $8.56 billion for the Health Resources and Services Administration in the bill.

Centers for Disease Control and Prevention: CDC provides the foundation for our State and local public health departments, supporting a trained workforce, laboratory capacity and public health education communications systems. It is notable that more than 70 percent of CDC's budget supports public health and prevention activities by State and local health organizations and agencies, national public health partners and academic institutions. We believe Congress should support CDC as an agency and urge the Senate to match the nearly $8.3 billion provided for CDC in the House bill. We are grateful for the important increases provided for CDC programs in fiscal year 2019 and urge Congress to build upon these investments to strengthen all of CDC's programs most of which remain woefully underfunded. We also urge your continued support for the Prevention and Public Health Fund which currently makes up approximately 10 percent of CDC's budget.

CDC serves as the command center for the Nation's public health defense system against emerging and reemerging infectious diseases. From aiding in the surveillance, detection and prevention of the Zika virus to playing a lead role in the control of Ebola in West Africa and detecting and responding to cases in the U.S., to monitoring and investigating disease outbreaks in the U.S., to pandemic flu preparedness, to educating the public about the value and importance of vaccines, CDC is the Nation's—and the world's—expert resource and response center, coordinating communications and action and serving as the laboratory reference center for identifying, testing and characterizing potential agents of biological, chemical and radiological terrorism, emerging infectious diseases and other public health emergencies. CDC oversees immunization programs for children, adolescents and adults, and is a global partner in the ongoing effort to eradicate polio worldwide. Childhood immunizations provide one of the best returns on investment of any public health program. For every dollar spent on childhood vaccines to prevent thirteen diseases, more than $10 is saved in direct and indirect costs. Over the past 20 years, CDC estimates childhood immunizations have prevented 732,000 deaths and 322 million illnesses. Congress must support efforts to stop current vaccine-preventable disease outbreaks and prevent more from occurring. We urge you to provide adequate funding for CDC's public health emergency preparedness and immunization programs.

In 2017, nearly 40,000 Americans lost their lives due to gun violence. Unfortunately, Congress has failed to provide any funding for research into this deadly epidemic, which has stymied progress on gun violence prevention research for the past 20 years. Congress can correct this by providing CDC with $50 million in fiscal year 2020 for gun violence prevention research. This funding is needed to allow CDC to conduct research into important issues including the best ways to prevent unintended firearm injuries and fatalities among women and children; the most effective methods to prevent firearm-related suicides; and the measures that can best prevent the next shooting at a school or public place. We are pleased that the House bill provides $25 million to both CDC and the National Institutes of Health, for a total of $50 million, to conduct this research.

CDC's National Center for Environmental Health works to control asthma, protect against threats associated with natural disasters and climate change, reduce and monitor exposure to lead and other environmental health hazards and ensure access to safe and clean water. We urge you to match the House level of $243 million for NCEH in fiscal year 2020, including a $5 million increase for CDC's Climate and Health program. Climate change is happening now and is threating our health in many ways including through the increased spread of vector-borne diseases, degraded air quality from ozone pollution and wildfire smoke, hotter temperatures and more extreme weather events. Increased funding will allow CDC to fund an additional 14 health departments to help them prepare for and respond to the health impacts of climate change in their communities. CDC will also be able to begin to evaluate the work of existing grantees to identify and share best practices with communities nationwide.

Programs under the National Center for Chronic Disease Prevention and Health Promotion address heart disease, stroke, cancer, diabetes and tobacco use that are the leading causes of death and disability in the U.S. and are also among the most costly to our health system. CDC provides funding for State programs to prevent disease, conduct surveillance to collect data on disease prevalence, monitor intervention efforts and translate scientific findings into public health practice in our communities. We once again strongly oppose the administration's proposal to block grant and cut funding for many of these programs.

Health Resources and Services Administration: HRSA is the primary Federal agency dedicated to improving health outcomes and achieving health equity. HRSA's 90-plus programs and more than 3,000 grantees support tens of millions of geographically isolated, economically or medically vulnerable people, in every U.S. State and territory, to achieve improved health outcomes by increasing access to quality healthcare and services; fostering a healthcare workforce able to address current and emerging needs; enhance population health and address health disparities through community partnerships; and promote transparency and accountability within the healthcare system.

We are grateful for the increases provided for HRSA programs in fiscal year 2019, however HRSA's discretionary budget authority remains nearly 20 percent below the fiscal year 2010 level (adjusted for inflation). We recommend Congress build upon the important increases they provided for HRSA programs in fiscal year 2019 and provide $8.56 billion for HRSA's total discretionary budget authority in fiscal year 2020.

HRSA programs and grantees are providing innovative and successful solutions to some of the Nation's greatest healthcare challenges, including the rising maternal mortality rate, the severe shortage of health professionals, the high cost of healthcare and behavioral health issues related to substance use disorder, including opioid misuse. Additional funding will allow HRSA to build upon these successes and pave the way for new achievements by supporting critical HRSA programs, including:

Primary Health Care that supports over 11,000 community health center sites in medically underserved communities across the U.S., providing access to high-quality preventive and primary care to more than 28 million people including over 8.4 million children and 350,000 veterans.

Health Workforce supports the health workforce across the entire training continuum and offers scholarship and loan repayment programs to ensure a well-prepared, well-distributed and diverse workforce that is ready to meet the current and evolving healthcare needs of the Nation.

Maternal and Child Health supports initiatives that promote optimal health, reduce infant mortality, minimize disparities, prevent chronic conditions and improve access to quality healthcare for vulnerable women, infants and children; and serves more than 56 million people through the MCH block grant.

HIV/AIDS delivers a comprehensive and robust system of care to more than 550,000 individuals impacted by HIV/AIDS, improving health outcomes for people with HIV and reducing the chance of others becoming infected; and provides training for health professionals treating people with HIV/AIDS. HRSA's Ryan White HIV/AIDS Program effectively engages clients in comprehensive care and treatment, including increasing access to HIV medication, which has resulted in 86 percent of clients achieving viral suppression, compared to just 59 percent of all people living with HIV nationwide.

Family Planning Title X services ensure access to comprehensive family planning and related preventive health services to more than 4 million people, thereby reducing unintended pregnancy rates, limiting transmission of sexually transmitted infections and increasing early detection of breast and cervical cancer.

Rural Health supports community and State-based solutions to improve efficiencies in delivering rural health services and expand access, including supporting activities that aim to increase access to opioid treatment in rural areas, leverage the use of health information technology and telehealth and advise on rural health policy issues.

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

Thank you for considering our views on fiscal year 2020 funding for these critical Federal public health agencies and programs.

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

Prepared Statement of the American Society for Engineering Education

SUMMARY

This written testimony is submitted on behalf of the American Society for Engineering Education (ASEE) to the Senate Subcommittee on Labor, Health and Human Services, Education, and Related Agencies for the official record. ASEE appreciates the Committee's support for the Department of Education (ED) in fiscal year 2019 and asks you to robustly fund student aid, teacher preparation, and STEM programs in fiscal year 2020. Additionally, ASEE requests Federal funding to support initiatives aimed at increasing the diversity of the STEM pipeline and support for Minority Serving Institutions (MSI). The strong support of the National Institutes of Health (NIH) in fiscal year 2019 was greatly appreciated and ASEE requests continued support of NIH.

WRITTEN TESTIMONY

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

Student Aid

Student aid programs like Pell Grants, Federal Work-Study (FWS), TRIO, and others make higher education accessible and affordable for millions of students. ASEE joins the higher education community in requesting funding to support a maximum Pell Award of $6,345. Pell Grants are essential to low-income students being able to afford higher education. These awards are vital in helping students access the significant life and career impacts that higher education provides. ASEE requests funding for FWS at $1.434 billion and $1.028 billion for Supplemental Educational Opportunity Grant (SEOG). These programs are need-based, and often this aid provides the resources a student needs to complete their education. ASEE asks the Committee to consider ways to support work-based learning, such as co-operative education and apprenticeships, within the FWS program. ASEE firmly believes in ensuring access to engineering and engineering technology education for all students, not just those who can afford it. Ensuring student aid programs for graduate students is also very important. ASEE requests funding for the Graduate Assistance in Areas of National Need (GAANN) program, which provides fellowships, through academic departments and programs of institutions of higher education, to assist graduate students with excellent records who demonstrate financial need. ASEE requests $48 million for GAANN. Engineering education provides a proven pathway to the middle class, especially for students from low-income backgrounds.

Teacher Preparation

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

STEM

Support for Science, Technology, Engineering, and Mathematics (STEM) continues to grow and ASEE appreciates the funding increases many STEM programs received in fiscal year 2019. ASEE supports funding for Title IV of ESEA at its authorized amount of $1.6 billion, which will allow States and school districts additional resources to pursue STEM programs. ASEE supports robust funding for STEM programs for higher education students including the Hispanic-Serving Institutions (HSI) STEM and Minority Science and Engineering Improvement (MSEIP) programs. The STEM workforce is a driving force behind innovation and our economic development. These and other programs targeted towards increasing the representation of historically underrepresented populations, including women, will ensure a healthy STEM workforce pipeline.

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

NIBIB is the major NIH Institute focused on engineering applications to human health and training the next generation of biomedical engineers. ASEE is grateful to the committee for its strong bipartisan support of the NIH in fiscal year 2019. NIBIB funding is critical for the development of devices and tools that can improve the detection, treatment, and prevention of disease, and also plays a critical role in assessing the effectiveness of new drugs and treatment procedures. NIBIB also supports training programs to enhance and expand education and training for the next generation biomedical engineering workforce. Through grant programs like the Enhancing Science, Technology, and Math Education Diversity Research Education Experiences, and Team-Based Design in Biomedical Engineering Education, NIBIB is committed to supporting all stages of the biomedical engineering career pathway and increasing the participation of traditionally underrepresented groups in engineering. ASEE urges the Committee to provide NIH with $41.6 billion in fiscal year 2020 so that NIBIB can continue to support critical biomedical engineering research and training.

CONCLUSION

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

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

PREPARED STATEMENT OF THE AMERICAN SOCIETY FOR MICROBIOLOGY

On behalf of its 32,000 members, the American Society for Microbiology (ASM) thanks Chairman Blunt, Ranking Member Murray, and members of the Senate Appropriations Subcommittee on Labor, Health and Human Services, Education and

Related Agencies for holding a hearing on the response to the Ebola outbreak in the Democratic Republic of the Congo (DRC) and other emerging threats.

We also thank the Chairman, Ranking Member and the Subcommittee members for their unwavering support for medical research, as demonstrated by the $9 billion (30 percent) increase in funding for the National Institutes of Health (NIH) over the past four fiscal years. We urge the Subcommittee to make a strong investment in fiscal year 2020 in the Centers for Disease Control and Prevention (CDC), given its work in tandem with a well-funded NIH, and its role as a critical partner in maintaining global health security.

As an organization with an extensive global health program and scientists and public health workers on the front lines in countries like the DRC, ASM understands firsthand the importance of securing our borders against natural and intentional bio threats. Our human world is more interconnected than ever, and so is our microbial world. What happens in the environments in remote areas of the world can often spell the telltale signs of the next major outbreak, wherever we happen to live, because microbes are unimpeded by the construct of human borders.

At a time when we are still addressing threats like Ebola in Africa and seeing antimicrobial resistance rise, the drastic cuts proposed to these agencies in the President's fiscal year 2020 budget request to Congress are unthinkable. If enacted, these cuts would cripple our Nation's ability to respond to threats at home, regardless of where in the world they may originate. For this reason and because of their critical importance to our national security, our public health here in the United States, and our global leadership in advancing science, ASM urges Congress to reject the President's short-sighted cuts and continue to support robust funding for the NIH, the CDC, and programs under the Assistant Secretary for Preparedness and Response.

We also urge Congress to recommit to a Global Health Security Agenda (GHSA). GHSA is a critical program for international engagement and capacity building in public health. Funding for this effort is slated to end this year. Our GHSA investment has helped strengthen laboratory diagnostic capacity and reporting for surveillance in many countries, with proven results, and should continue.

Lastly, we urge the Senate to move quickly to pass legislation that reauthorizes the Pandemic and All-Hazards Preparedness Act (PAHPA), and that the Subcommittee support funding consistent with the reauthorization. The recent outbreaks of Ebola abroad and even outbreaks here in the United States of vaccine-preventable diseases like the measles demonstrate why this legislation is so critical. Our Nation's security calls for the need to prevent and mitigate a major disease outbreak, and the resources to build and sustain the infrastructure necessary for Federal and State governments to respond to potential and declared public health emergencies in a timely and coordinated manner.

Ebola will not be the last virus to evolve into a major health and security threat. The only way to stay ahead of the rapid evolution of microorganisms and the inevitable emergence of new diseases is to support infectious disease research and public health agencies that can prevent and respond rapidly to outbreaks. This requires robust, sustained and predictable funding, training of personnel, and safe and secure facilities.

ASM stands ready to assist Members of the Subcommittee and the Congress in supporting and strengthening these programs under the NIH, the CDC, and USAID to ensure global health security for the United States and our allies abroad.

ASM is the largest single life science society, composed of more than 32,000 scientists and health professionals. Our mission is to promote and advance the microbial sciences, including programs and initiatives funded by the Federal Government departments and agencies, by virtue of the pervasive role of microorganisms in health and society.

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 2020 appropriations. The American Society for Nutrition (ASN) respectfully requests at least $41.6 billion dollars for the National Institutes of Health (NIH) and $175 million dollars for the Centers for Disease Control and Prevention/National Center for Health Statistics (CDC/NCHS) in fiscal year 2020. ASN is dedicated to bringing together the world's top researchers to advance our knowledge and application of nutrition, and has more than 7,000 members working throughout academia, clinical practice, government, and industry.

NATIONAL INSTITUTES OF HEALTH

The NIH is the Nation's premier sponsor of biomedical research and is the agency responsible for conducting and supporting 86 percent of federally-funded basic and clinical nutrition research. Although nutrition and obesity research make up less than 8 percent of the NIH budget, some of the most promising nutrition-related research discoveries have been made possible by NIH support. NIH nutrition-related discoveries have impacted the way clinicians prevent and treat heart disease, cancer, diabetes and other chronic diseases. For example, from 2001 to 2011, the U.S. death rate from heart disease has fallen by about 39 percent and from stroke by about 35 percent.[1] However, the burden and risk factors remain high. With additional support for NIH, additional breakthroughs and discoveries to improve the health of all Americans will be made possible.

Investment in biomedical research generates new knowledge, improved health, and leads to innovation and long-term economic growth. From fiscal year 2003 to 2015, the NIH lost 22 percent of its capacity to fund research due to budget cuts, sequestration, and inflationary losses. Such economic stagnation is disruptive to training, careers, long-range projects and ultimately to progress. Since fiscal year 2016, Congress has begun to restore the NIH budget but there is much work to be done; in real dollars, the NIH budget is still 16 percent below the fiscal year 2003 level. ASN recommends at least $41.6 billion dollars for NIH in fiscal year 2020 to support NIH nutrition-related research that will lead to important disease prevention and cures. A budget of $41.6 billion will allow NIH to support at least 400 additional early career and early established investigators while still providing much needed increases to other parts of the portfolio. NIH needs sustainable and predictable budget growth to fulfill the full potential of biomedical research, including nutrition research, that is aimed at improving the health and wellbeing of all Americans, as well as global populations.

CENTERS FOR DISEASE CONTROL AND PREVENTION NATIONAL CENTER FOR HEALTH STATISTICS

The National Center for Health Statistics, housed within the Centers for Disease Control and Prevention, is the Nation's principal health statistics agency. ASN recommends a fiscal year 2020 funding level of $175 million dollars for NCHS to help ensure uninterrupted collection of vital health and nutrition statistics and help cover the costs needed for technology and information security maintenance and upgrades that are necessary to replace aging survey infrastructure. The U.S. is a leader in this area and a decade of flat-funding has taken a significant toll on NCHS's ability to keep pace.

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

Nutrition monitoring conducted by the Department of Health and Human Services in partnership with the U.S. Department of Agriculture/Agricultural Research Service is a unique and critically important surveillance function in which dietary intake, nutritional status, and health status are evaluated in a rigorous and standardized manner. Nutrition monitoring is an inherently governmental function and findings are essential for multiple government agencies, as well as the public and private sector. Nutrition monitoring is essential to track what Americans are eating, inform nutrition and dietary guidance policy, evaluate the effectiveness and efficiency of nutrition assistance programs, and study nutrition-related disease outcomes. Funds are needed to ensure the continuation of this critical surveillance of the Nation's nutritional status and the many benefits it provides.

Through learning both what Americans eat and how their diets directly affect their health, the NCHS is able to monitor the prevalence of obesity and other chronic diseases in the U.S. and track the performance of preventive interventions, as well as assess 'nutrients of concern' such as calcium, iron, folate, iodine, vitamin D, and other micronutrients which are consumed in inadequate amounts by many subsets of our population. Data such as these are critical to guide policy development

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[1] https://www.heart.org/idc/groups/ahamah-public/@wcm/@sop/@smd/documents/downloadable/ucm__470704.pdf.

in health and nutrition, including food safety, food labeling, food assistance, military rations and dietary guidance. For example, NHANES data are used to determine funding levels for programs such as the Supplemental Nutrition Assistance Program (SNAP) and the Women, Infants, and Children (WIC) clinics, which provide nourishment to low-income women and children.

Thank you for the opportunity to submit testimony regarding fiscal year 2020 appropriations for the National Institutes of Health and the CDC/National Center for Health Statistics. Please contact John E. Courtney, Ph.D., ASN Executive Officer, at 9211 Corporate Boulevard, Suite 300, Rockville, Maryland 20850, jcourtney@nutrition.org or 240–428–3650, if ASN may provide further assistance.

Sincerely.

[This statement was submitted by Catherine J. Field, Ph.D., RD, President, American Society for Nutrition.]

Prepared Statement of the American Society of Clinical Oncology

The American Society of Clinical Oncology (ASCO), the world's leading professional organization representing over 45,000 physicians and other professionals who treat people with cancer, thanks this subcommittee for its long-standing commitment to support federally funded research at the NIH and NCI. ASCO applauds your leadership in securing a $2 billion increase for the NIH in fiscal year 2019. This strong commitment to scientific discovery will help the research community regain momentum and sustain our Nation's position as the world leader in biomedical research. We are in an exciting and promising era of medical research; new discoveries are leading to major improvements in the way we care for patients with cancer. Continued progress in preventing and treating cancer depends on consistent and reliable funding for research that provides the insight needed for better treatments and quality of life for all Americans. ASCO appreciates this opportunity to provide the following recommendations for fiscal year 2020 funding which build on our Nation's investment in biomedical research:

—*National Institutes of Health (NIH):* $41.6 billion
—*National Cancer Institute (NCI):* $6.522 billion

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

The NIH: A Good Investment

In fiscal year 2018, the NIH provided over $28 billion in extramural research to scientists in all 50 States and the District of Columbia. NIH research funding also supported more than 433,000 jobs and nearly $74 billion in economic activity last year.[1] Federal funding supported nearly one third of the studies highlighted in ASCO's 2019 Clinical Cancer Advances report, the Society's 14th annual report on progress against cancer. Some of the most notable federally funded advances highlighted in the 2019 report are:

—New combination of targeted therapies identified for rare form of thyroid cancer.
—First treatment approved to improve progression-free survival for rare Sarcoma.
—First promising therapy identified for rare cancer of the joints that occurs in young adults.
—Combination immunotherapy found to reduce brain metastases in people with melanoma.
—CAR–T therapy trials showing longer term benefits in patients with lymphoma.
—Common cancers detected early in investigational blood tests.
—Major trial identifies women who can safely skip adjuvant chemotherapy for breast cancer.
—New combination treatment halves hearing loss risk in children with hepatoblastoma.
—Link established between specific oral microbiome and the risk of colon, squamous cell, and esophageal cancers.

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[1] ASCO Clinical Cancer Advances 2019 Report; https://www.asco.org/research-progress/reports-studies/clinical-cancer-advances-2019.

Sustained and steady funding of the NIH and NCI is critical to maintaining the pace of scientific discovery and continued progress against cancer, such as the advances outlined above.

We appreciate that over the last few years Congress has prioritized Federal funding for biomedical research, increasing the NIH budget by $2 billion in fiscal year 2019, and providing an increase of $9 billion over the last four fiscal years. Despite Congress' efforts, however, the budget of both the NIH and NCI, when adjusted for biomedical inflation, remain below 2003 levels. In fact, if the NIH's budget had kept up with biomedical inflation since its doubling, it would be 8.4 percent, or $3.6 billion higher than it is now. Funding for our Nation's biomedical research infrastructure needs sustained increases to meet the possibility of today's science. Failure to continue the historic investment in research places health outcomes, scientific leadership, and economic growth at risk.

Capturing Opportunity: The Potential of Cancer Research

ASCO thanks appropriators for the continued inclusion of funding for the Beau Biden Cancer Moonshot Initiative in the fiscal year 2019. The NCI continues its work to achieve 10 years of cancer research progress in five. Specifically, the Cancer Moonshot Initiative is currently working towards modernizing clinical trials, establishing a direct patient engagement network, development of a national cancer data ecosystem, continued advances in precision oncology, and developing effective immunotherapies for a broader array of cancers, including pediatrics. Adequate funding is needed to make progress in each of these areas over the coming years. However, funding for this Initiative should supplement rather than supplant predictable increases in the underlying NCI budget. In fact, funding for the Initiative peaks in fiscal year 2019, and NCI will face a major drop in funding for the Initiative in fiscal year 2020, from $400 million in fiscal year 2019 to $195 million in fiscal year 2020, and will remain lower through fiscal year 2023 when funding for the Initiative ends, making it critical for NCI to receive greater baseline funding from Congress.

The NCI is the largest funder of cancer research in the world, and the majority of its funding goes directly towards supporting research at NCI and at cancer centers, hospitals, community clinics, and universities across the United States. However, despite NCI's modest funding increases over the last few years, these increases have not been proportional with the NIH's, nor has funding kept up with the growing number of research grants and applications as compared to other NIH Institutes. This means NCI is actually funding a smaller proportion of grant applications compared to previous years—12 percent of applications received funding in 2017 compared to 28 percent in 2017.[2] In fact, even after counting the additional funding NCI has received through the Cancer Moonshot Initiative, NCI's budget lags 15.6 percent, or $1.1 billion below what if would have been if funding had kept pace with biomedical inflation since fiscal year 2003.

Cancer Registries: Harnessing Data

ASCO also joins the broader cancer community in requesting $555 million for the Centers for Disease Control and Prevention's (CDC) Division of Cancer Prevention and Control (DCPC), and $70 million for the CDC's Cancer Registries Program. Funding for the DCPC has remained virtually flat for 9 years, rising just $1.2 million from fiscal year 2010 ($370.3 million) to fiscal year 2019 ($371.5 million). Cancer registries are a critical tool for providers and researchers, providing unparalleled cancer surveillance, identifying emerging trends amongst different patient cohorts, illustrating the impact of early detection, and showing the impact of treatment advances on cancer outcomes. Registries allow providers to collect data in real time and improve cancer research, public health interventions and treatment protocols. Additionally, these registries benefit patient cohorts that may be left out of traditional clinical trials, like racial and ethnic minorities, women and children, and rural populations.

Supporting Pillars of Care: Clinical Trials and Translational Research

NIH-funded translational research and clinical trials have significantly improved the standard of care in many diseases. Federal funding and targeted programs extend cutting edge science to communities and diverse participants across the United States. Clinical trials and translational research provide cost-effective treatment options for many common cancers. They yield insight critical to the development of targeted therapies, which identify patients most likely to benefit and help patients

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[2] National Institutes of Health: Research project success rates by NIH institute. https://report.nih.gov/success__rates/Success__ByIC.cfm.

who will not benefit avoid the cost and pain of treatment unlikely to help them. This is where science becomes practice-changing for patients in America.

ASCO has developed the Targeted Agent and Profiling Utilization Registry (TAPUR(tm)) Study, which provides access to certain targeted therapies for patients who are age twelve and older and who have been identified as candidates for benefitting from those treatments. The TAPUR Study evaluates use of these molecularly targeted anti-cancer drugs and collects data on clinical outcomes. As of March 5, 2019, there are more than 1350 participants enrolled in the TAPUR Study at more than 110 sites in twenty States. Without Federal investment spurring the pipeline of new cancer treatments, studies such as TAPUR would not be possible.

To maintain access to research for cancer patients, ASCO urges a substantial increase in funding for the National Clinical Trials Network (NCTN) and NCI Community Oncology Research Program (NCORP). ASCO is very concerned that Federal funding is not at a level that allows NCI to sustain this important network of community practices that engage in clinical research-and provide an important source of patients willing to participate. An increase in NCI's budget would enable the Institute to maintain or increase the number of accruals to trials and cover the cost of conducting the research.

Bringing Research to the Patient: NIH Funding Spurs Development of New Treatments

Modern cancer research delivers new treatments to patients faster than ever, thanks to continuing innovation in research and regulatory infrastructure. In 2018 the FDA approved 23 cancer therapies for more than seventeen different types of cancer,[3] and expanded the use of adoptive cell immunotherapy, also known as CAR–T cell therapy, which utilizes the patient's own immune cells to fight cancer. Since 1992 there have been nearly 25 consecutive years of decline in overall incidence and mortality rates for all types of cancer.[4] In addition, the number of people living 5 years or more after a cancer diagnosis is projected to rise 31 percent by 2026,[5] representing an increase of more than four million survivors in less than a decade. Cancer research, including the advances in this report, helps make progress possible.

ASCO again thanks the subcommittee for its continued support of cancer patients in the U.S. through funding for the NIH and NCI. We look forward to working with all members of the subcommittee on an fiscal year 2020 budget that continues to advance U.S. cancer research. Please contact Kristin Palmer at Kristin.Palmer@asco.org with any questions.

[This statement was submitted by Monica Bertagnolli, MD, FASCO, President, American Society of Clinical Oncology.]

PREPARED STATEMENT OF THE AMERICAN SOCIETY OF GENE & CELL THERAPY

Dear Chairman Blunt, Ranking Member Murray, and Subcommittee Members:

Thank you for the opportunity to provide this testimony on behalf of the American Society of Gene & Cell Therapy (ASGCT). ASGCT is a membership organization consisting of scientists, physicians, and other professionals involved in the gene and cell therapy fields in settings such as universities, hospitals, government agencies, foundations, and biotechnology and pharmaceutical companies.

The Society respectfully requests robust fiscal year 2020 appropriations to the National Institutes of Health to support the biomedical research that can advance future gene and cell therapies. Further funding of gene and cell therapy research has the potential to accelerate the discovery and clinical application of more safe, effective, and innovative genetic and cellular therapies to alleviate and ease human disease, which is a core component of the mission of ASGCT.

SIGNIFICANCE OF NIH RESEARCH FUNDING FOR GENE AND CELL THERAPY

NIH funding is crucial to support basic research on biological targets as well as applied research on new molecular entities, which both contribute to new thera-

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[3] CenterWatch; FDA Approved Drugs for Oncology; https://www.centerwatch.com/drug-information/fda-approved-drugs/therapeutic-area/12/oncology.

[4] Bluethmann SM, Mariotto AB, Rowland JH: Anticipating the "silver tsunami": Prevalence trajectories and comorbidity burden among older cancer survivors in the United States. Cancer Epidemiol Biomarkers Prev 25:1029–1036, 2016.

[5] Cronin KA, Lake AJ, Scott S, et al: Annual report to the nation on the status of cancer, part I: National cancer statistics. Cancer 124:2785–2800, 2018.

peutic approvals.[1] NIH funding contributed to published research associated with every one of the 210 new drugs approved by the Food and Drug Administration from 2010—2016.[1] The development of new therapeutics therefore relies upon this investment, in order to accelerate the development of new gene therapies for treatment of as many genetic diseases as possible.

For example, grants provided by the Federal Government have funded research that has led to clinical trials to treat sickle cell disease. Sickle cell disease is caused by a single gene mutation that results in a lack of production of beta globin, a component of hemoglobin (a protein in red blood cells). This lack of beta globin causes rigid, sickle-shaped red blood cells that do not carry oxygen as well as normal cells.[2] Reduced blood flow and oxygen can cause weakness, fatigue, slowed growth, severe pain and other serious complications, such as harm to a patient's liver, brain, eyes, and lungs, among other organs.[3]

Cincinnati Children's Hospital, which receives the majority of its funding through the NIH and ranks second among pediatric hospitals in funding from the agency, has established a Comprehensive Sickle Cell Center to combat this disease.[3] ARU–1801, originally developed in Dr. Punam Malik's laboratory at Cincinnati Children's Hospital, is an investigational gene therapy for sickle cell disease that aims to increase functioning red blood cells by removing a patient's own stem cells, inserting a functioning gene into the cells outside the body, and delivering the cells back into the patient.[4] Preliminary findings in Phase 1/2 clinical trials showed a substantial reduction in disease symptoms-near elimination of chronic pain and sickling events, and improved anemia.[5]

Federally-funded research has benefits that stretch beyond the scope of clinical development. In addition to its direct contributions to gene therapy-related research, NIH-funded research is responsible for the creation of approximately 440,000 jobs and $69 billion in economic stimulation.[6] Furthermore, studies show that NIH investments in biomedical research stimulate increased private investment; with every dollar of increase in public clinical research stimulating $2.35 of industry investment at 3 years.[7] This economic stimulation is even higher for gene-related research, with a Federal investment of $3.8 billion in the Human Genome Project from 1988 to 2003 helping to drive $796 billion in economic output, which is a return of $141 for every $1 invested.[8]

Need for Additional Gene and Cell Therapy Research

Progress in clinical trials of gene therapies and gene-modified cell therapies exemplify the vast medical progress that NIH research has contributed to in these areas, which provides hope for the future. However, considerable additional scientific study will be necessary for gene and cell therapies to reach their potential to transform the lives of patients with multiple additional diseases. Many of the diseases for which gene therapy offers great promise are rare inherited disorders. Of the 7,000 rare diseases that exist, 95 percent have no current treatment.[9]

Continued strong funding for multiple institutes and centers of the NIH can support gene and cell therapy research to address this immense unmet need and the resulting human and economic costs of diseases such as hemophilia, muscular dystrophy, and retinal disorders that collectively impact the lives of 10 percent of the

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[1] Cleary, E.G., Beierlein, J.M., Khanuja, N.S., McNamee, L.M., Ledley, F.D. (2018). Contribution of NIH funding to new drug approvals. In Snyder, S. H. (Ed.) Proceedings of the National Academy of Sciences, 201715368, doi: 10.1073/pnas.1715368115.

[2] Sickle Cell Disease. (n.d.). Retrieved from https://www.nhlbi.nih.gov/health-topics/sickle-cell-disease.

[3] Funding Growth Fuels Discovery. (n.d.). Retrieved from https://www.cincinnatichildrens.org/research/cincinnati/ccrf/funding.

[4] Biopharmaceutical Drug Development. (2019). Retrieved from https://roivant.com/#pipeline.

[5] Early Clinical Trial Data Show Gene Therapy Reversing Sickle Cell Anemia. (2018). Retrieved from https://www.cincinnatichildrens.org/news/release/2018/gene-therapy.

[6] United for Medical Research: NIH's role in sustaining the U.S. economy: 2018 update. http://www.unitedformedicalresearch.com/wp-content/uploads/2018/02/NIHs-Role-in-Sustaining-the-U.S.-Economy-2018-Update-FINAL.pdf.

[7] Heymach, J., Krilov, L., Alberg, A., Baxer, N.,Chang, S. M., Corcoran, R., ... Burstein, H. Clinical Cancer Advances 2018: Annual Report on Progress Against Cancer From the American Society of Clinical Oncology. Journal of Clinical Oncology 2018 36(10), 1020–1044.

[8] Accelerating Biomedical Research Act, H.R. 5455, 115th Cong. (2018).

[9] Institute of Medicine (U.S.) Committee on Accelerating Rare Diseases Research and Orphan Product Development; Field, M.J., & Boat, T.F., editors. Rare Diseases and Orphan Products: Accelerating Research and Development. Washington (DC): National Academies Press (U.S.); 2010. Available from www.ncbi.nlm.nih.gov/books/NBK56189. doi: 10.17226/12953.

U.S. population.[10] Children with some hereditary diseases cannot walk, or even breathe or swallow on their own. Tragically, many of these children die young or become severely disabled by adolescence. For diseases with longer life expectancy, such as hemophilia, patients face a lifetime of intensive and expensive medical care. For example, the average lifetime cost of treating hemophilia A with bypassing agent prophylaxis can range from $90 million to $99 million.[11] Developing potentially durable, often one-time gene therapies for these diseases will require significant research funding, which will ease or potentially end the human suffering, and in some cases the high current medical costs, that they currently incur.

APPROPRIATIONS REQUEST

Since gene and cell therapies are types of regenerative medicine, ASGCT is grateful for the funding authorized by the 21st Century Cures Act for the Regenerative Medicine Innovation Project (RMIP).[12] Appropriations of a total of $22 million in fiscal year 2017—fiscal year 2019 for RMIP, as authorized, are greatly appreciated, resulting in funding of 16 grants over the last 2 years.[13] The Society requests that the $8 million authorized by the Cures Act for fiscal year 2020 is appropriated for this initiative.

While NIH funding increases have been generous over the past 4 years, the need remains to maintain global leadership in medical innovation and to compensate for funding that still lags behind funding levels at the end of the budget-doubling initiative which ended in 2003, when adjusted for biomedical research inflation.[14] This era resulted in the grant application success rate diminishing to below historic averages. Without the current budget restraints, the grant application success rate could be closer to one in every three applications. However, fiscal year 2018 produced a grant application success rate of 22.7 percent.[15] Increases in funding to the NIH in general, and to the gene and cell therapy fields in particular, need to continue to support the potential progress in the development of these transformative treatments. The Society also requests at least a $2 billion increase in NIH funding for fiscal year 2020, as has also been proposed by the House Labor, Health and Human Services, Education and Related Agencies Appropriations Subcommittee.

In conclusion, because NIH funding can contribute to the development of new gene and cell therapies to treat diseases with great unmet medical need, ASGCT encourages the Senate Committee on Appropriations, Subcommittee on Labor, Health and Human Services, Education, and Related Agencies to provide robust appropriations in its fiscal year 2020 funding to the many institutes and centers of the NIH that engage in gene and cell therapy related research. The Society also advocates for continued separate, specific appropriations to continue to fund the Regenerative Medicine Innovation Project. We appreciate your consideration of these comments.

Sincerely,

Guangping Gao, PhD
President

PREPARED STATEMENT OF THE AMERICAN SOCIETY OF HEMATOLOGY

The American Society of Hematology (ASH) represents more than 17,000 clinicians and scientists committed to the study and treatment of blood and blood-related diseases. These diseases encompass malignant disorders such as leukemia, lymphoma, and myeloma; life-threatening conditions, including thrombosis and bleeding disorders; and congenital diseases such as sickle cell anemia, thalassemia, and hemophilia. Hematologists have been pioneers in the fields of bone marrow transplantation, stem cell biology and regenerative medicine, and gene and immunotherapy.

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[10] Maude, S., Laetsch, T., Buechner, J., Rives, S., Boyer, M., Bittencourt, H., ... Baruchel, A. (2018). Tisagenlecleucel in children and young adults with B-cell lymphoblastic leukemia. N Engl J Med 378, 439–448.

[11] Pearson, S. (2018). Can We Determine "Value-based" Prices for Gene Therapies? Lecture presented at ASGCT Value Summit, Washington, DC.

[12] 21st Century Cures Act, H.R. 34, 114th Cong. (2015).

[13] Funding Opportunities. (2018). Retrieved from https://www.nih.gov/rmi/funding-opportunities.

[14] Budget. (2019). Retrieved from https://www.nih.gov/about-nih/what-we-do/budget.

[15] Success Rates—NIH Research Portfolio Online Reporting Tools (RePORT). (2019). Retrieved from https://report.nih.gov/success__rates/.

FISCAL YEAR 2020 REQUEST: NIH FUNDING

ASH thanks Congress for the robust bipartisan support that has resulted in several consecutive years of welcome and much needed funding increases for the National Institutes of Health (NIH), including the $2 billion increase that Congress provided in fiscal year 2019. For fiscal year 2020, ASH strongly supports the Ad Hoc Group for Medical Research recommendation that NIH receive at least $41.6 billion. This funding level, supported by more than 300 other stakeholder organizations, would allow for meaningful growth above inflation in the base budget that would expand NIH's capacity to support promising science in all disciplines. It also would ensure that funding from the Innovation Account established in the 21st Century Cures Act would supplement the agency's base budget, as intended, through dedicated funding for specific programs.

American biomedical research has led to new medical treatments, saved innumerable lives, reduced human suffering, and spawned entire new industries, none of which would have been possible without support from NIH. Hematology research, funded by many institutes at the NIH, including the National Heart, Lung and Blood Institute (NHLBI), the National Cancer Institute (NCI), the National Institute of Diabetes, Digestive and Kidney Diseases (NIDDK), and the National Institute on Aging (NIA), has been an important component of this investment in the Nation's health.

With the advances gained through an increasingly sophisticated understanding of how the blood system functions, hematologists have changed the face of medicine through their dedication to improving the lives of patients. As a result, children are routinely cured of acute lymphoblastic leukemia (ALL); more than 90 percent of patients with acute promyelocytic leukemia (APL) are cured with a drug derived from vitamin A; older patients suffering from previously lethal chronic myeloid leukemia (CML) are now effectively treated with well-tolerated pills; and patients with multiple myeloma are treated with new classes of drugs. Hematology advances also help patients with other types of cancers, heart disease, and stroke. Basic research on blood has aided physicians who treat patients with heart disease, strokes, end-stage renal disease, cancer, and AIDS.

However, while some blood disorders have benefited from tremendous progress in clinical research and development of new therapies, other areas have continuing challenges and have evaded effective treatment to date. A wide variety of blood-related diseases—from malignancies such as lymphoma and leukemia to non-malignant diseases such as sickle cell disease, platelet and coagulation disorders, and orphan diseases of the hematopoietic system—continue to be associated with significant morbidity and mortality and demand attention to reduce their burden and improve quality of care nationwide.

FISCAL YEAR 2020 REQUEST: REPORT LANGUAGE SUPPORTING GENE AND CELLULAR THERAPIES

ASH is encouraged that there are a number of gene and cellular therapies in clinical trials that hold tremendous promise for patients. The approval of the first chimeric antigen receptor T-cell (CAR–T) therapy by the Food and Drug Administration (FDA) in August 2017 marked an important shift in the blood cancer treatment paradigm. CAR–T therapy is an innovative treatment for certain patients with leukemia and lymphoma.

While these therapies are potentially curative in many patients who have typically exhausted all other treatment options, patient access is currently limited because Medicare reimbursement falls significantly short of covering the high cost of these therapies, leading to concern that if reimbursement for these therapies does not improve, it will threaten innovation in this field. To support continued innovation and ensure patient access, the Society urges the inclusion of report language requiring all of the Department of Health and Human Services (HHS) agencies involved in the research, approval, and reimbursement for gene and cellular therapies, including NIH, the FDA, and the Centers for Medicare and Medicaid Services (CMS), to proactively harmonize their policies to ensure patients will have access to medically appropriate, approved gene and cellular therapies.

FISCAL YEAR 2020 REQUEST: CENTERS FOR DISEASE CONTROL AND PREVENTION (CDC)

The Society also recognizes the important role of the Centers for Disease Control and Prevention (CDC) in preventing and controlling clotting, bleeding, and other hematologic disorders.

Sickle cell disease (SCD) is an inherited, lifelong disorder affecting nearly 100,000 Americans. Individuals with the disease produce abnormal hemoglobin which results in their red blood cells becoming rigid and sickle-shaped, causing them to get stuck in blood vessels and block blood and oxygen flow to the body. SCD complications include severe pain, stroke, organ damage, and in some cases premature death. Though new approaches to managing SCD have led to improvements in diagnosis and supportive care, many people living with the disease are unable to access quality care and are limited by a lack of effective treatment options.

Surveillance is necessary to improve the understanding of outcomes and healthcare system utilization patterns, increase evidence for public health programs, and establish cost-effective practices to improve and extend the lives of people with SCD. With funding from the CDC Foundation, CDC has established a population-based data collection system to gather and analyze longitudinal data about people living in the U.S. with SCD. However, due to limited funding, implementation of the program has occurred in only two States—California and Georgia (representing approximately 10 percent of the U.S. SCD population).

CDC's SCD Data Collection Program should be maintained and expanded to include additional States with the goal of covering the majority of the U.S. SCD population over the next 5 years. In order for expanded data collection to become a reality, funding must be provided. The Sickle Cell Disease and Other Heritable Blood Disorders Research, Surveillance, Prevention, and Treatment Act of 2018 (Public Law 115–327) authorizes CDC to award SCD data collection grants to States, academic institutions, and non-profit organizations to gather information on the prevalence of SCD and health outcomes, complications, and treatment that people with SCD experience. For fiscal year 2020, the Society urges the Subcommittee to provide at least $2 million for SCD data collection within the CDC's National Center for Birth Defects and Developmental Disabilities, Division of Blood Disorders. This funding would allow CDC to expand the Data Collection Program to include additional States, with the goal of covering the majority of the U.S. SCD population over the next 5 years.

Additionally, ASH supports the public health community's request for at least $7.8 billion in funding for the CDC in fiscal year 2020. This funding level would build upon the funding increase Congress provided CDC in fiscal year 2019 and strengthen all of CDC's programs. ASH also urges continued support of the Public Health and Prevention Fund which has supported many critical projects at CDC, including investments in health-care associated infections. Currently the fund comprises more than 10 percent of CDC's budget. ASH is concerned about the repeated efforts to eliminate this fund because of the budgetary pressure this would place on other programs within the Subcommittee's jurisdiction.

Thank you again for the opportunity to submit testimony. Please contact ASH Senior Manager, Legislative Advocacy Tracy Roades at troades@hematology.org, if you have any questions or need further information concerning hematology research or ASH's fiscal year 2020 requests.

PREPARED STATEMENT OF THE AMERICAN SOCIETY OF HUMAN GENETICS

The American Society of Human Genetics (ASHG) thanks the Subcommittee for its continued support and leadership in funding the National Institutes of Health (NIH). The $2 billion increase provided for fiscal year 2019 reinforced our Nation's commitment to the health and well-being of all Americans by investing in biomedical research and scientific innovation. ASHG urges the Subcommittee to appropriate $41.6 billion for the NIH in fiscal year 2020.

My name is Tony Wynshaw-Boris. I am a professor and chair of the Department of Genetics and Genome Sciences at Case Western Reserve University. My laboratory studies the biology, specifically the genetics, of the development and function of the brain.

TRANSFORMING HUMAN HEALTH WITH GENOMICS

The transformative impact of genetics research for fundamental scientific knowledge and health applications is profound. Thanks to decades of sustained investment in basic and applied research, we are moving rapidly into an exciting new era of genetic investigation, novel application, diagnosis, and treatment. Due to NIH funding of the development of innovative sequencing technologies, it is now possible to sequence an individual's genome rapidly and cost-effectively. Remarkably, whereas fifteen years ago it cost tens of millions of dollars to sequence a human genome, today it can be done for around a thousand dollars in about a day.[1] From diagnosis to prognosis and treatment, this now-affordable and accessible data about genetic risk and resiliency for individuals and populations is ushering in a new era of precision medicine. Genetic and genomic approaches are driving novel discoveries across the spectrum of biomedical research. These advances are a central component of the research agenda of most NIH Institutes and Centers. For fiscal year 2017, $3.3 billion of NIH's $34.2 billion budget was spent on human genome-associated research projects.[2]

To realize the benefits of genetics and genomics research for all people, NIH-funded basic, translational, and clinical genetics research must continue if we are to fuel further progress. An illustrative example is cancer. Today, researchers have discovered more than 50 hereditary cancer syndromes.[3] Screening for cancer-causing mutations as a risk indicator, such as mutations in the genes BRCA1 and BRCA2, allows for increased monitoring and early intervention strategies. Sequencing tumors for changes that may identify effective drugs for that particular tumor can be used to guide treatment and improve prognosis. Finally, the recent approval by the Food and Drug Administration (FDA) of two gene therapies, Kymriah and Yescarta for treatment of acute lymphoblastic leukemia and B cell lymphoma respectively, marks an important breakthrough in cancer treatment options.[4] It is essential to continue support and expand research to develop targeted therapies for the millions of patients across our country affected by numerous other cancers.

Another example of progress and future promise can be found with opioid addiction—a national crisis with increasing burden on public health. NIH-supported genomics research is revealing new insights into the complex causes of addiction. Genome-wide association studies have linked numerous genetic variants to increased risk of opioid dependence, vulnerability to pain, and subsequent addiction.[5] We are also learning more about how genetics affects how the body breaks down opioids and other drugs. Clinics and hospitals have started using this information to guide pain management options.[6]

Other studies are focusing on the link between genomics and infectious diseases. Scientists recently discovered that a genetic variant in a gene for an antiviral protein is related to the severity of influenza.[7] An ongoing clinical trial is testing how genetic variants in flu vaccine recipients affects their protection from the flu.[8]

The discovery of CRISPR-Cas9 as a gene-editing technique in research laboratories holds promise as an exciting new approach to treating diseases. Gene-editing methods can precisely modify a DNA sequence in a cell to correct the gene variant that is causing disease. Multiple clinical trials are underway testing gene-editing strategies as treatments and even cures for diseases such as cancer, sickle cell anemia, and inherited childhood blindness.[9]

THE IMPACT OF NIH-FUNDED ACTIVITIES EXTENDS BEYOND PUBLIC HEALTH

Return on Federal funding for NIH can also be quantified by its economic impact. In fiscal year 2017, approximately 83 percent of the budget was allocated to more than 2,500 universities and institutions across every State, supported over 400,000 jobs and stimulated $69 billion in economic activity.[10] An example of this is Yescarta, noted above, which was a key product in the success of Kite Pharma, which was acquired for nearly $12 billion by another successful American company, Gilead Sciences. Likewise, we see a remarkable effect in the genomics research field. The Human Genome Project alone, and subsequent research has been shown to yield a total economic output of roughly $1 trillion and $55 billion in tax revenues over a 24-year span.[11] Each dollar invested in genomics research contributed $65 to the U.S. economy.

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[1] https://www.genome.gov/10000008/budget-and-financial-information/.

[2] https://report.nih.gov/categorical__spending.aspx.

[3] https://www.cancer.gov/about-cancer/causes-prevention/genetics/genetic-testing-fact-sheet.

[4] https://www.cancer.gov/news-events/cancer-currents-blog/2018/tisagenlecleucel-fda-lymphoma.

[5] Hu, R. et al. 2018. ANCO-GeneDB: annotations and comprehensive analysis of candidate genes for alcohol, nicotine, cocaine and opioid dependence. Database 2018.

[6] Cavallari, L.H. et al. 2019. Multi-site investigation of strategies for the clinical implementation of CYP2D6 genotyping to guide drug prescribing. Genetics in Medicine 2019.

[7] Allen, E.K. et al. 2017. SNP-mediated disruption of CTCF binding at the IFITM3 promoter is associated with risk of severe influenza in humans. Nature Medicine 23, 975–983.

[8] http://med.stanford.edu/vaccines/clinical__trials.html.

[9] https://clinicaltrials.gov/.

[10] http://www.unitedformedicalresearch.com/advocacy__reports/nihs-role-in-sustaining-the-u-s-economy2018-update/.

[11] https://web.ornl.gov/sci/techresources/Human__Genome/publicat/2013BattelleReportImpact-of-Genomics-on-the-US-Economy.pdf.

Given NIH's significant impact in many facets of the lives of our people and the growth and competitiveness of our economy, ASHG joins the Federation of American Societies for Experimental Biology (FASEB), and the Ad Hoc Group for Medical Research in recommending a $41.6 billion budget for NIH for fiscal year 2020.

The American Society of Human Genetics (ASHG), founded in 1948, is the primary professional membership organization for human genetics specialists worldwide. The Society's nearly 8,000 members include researchers, academicians, clinicians, laboratory practice professionals, genetic counselors, nurses and others who have a special interest in the field of human genetics.

[This statement was submitted by Anthony Wynshaw-Boris, MD, PhD, President-Elect, American Society of Human Genetics.]

PREPARED STATEMENT OF THE AMERICAN SOCIETY OF TROPICAL MEDICINE AND HYGIENE

The American Society of Tropical Medicine and Hygiene (ASTMH)—the largest international scientific organization of experts dedicated to reducing the worldwide burden of tropical infectious diseases and improving global health—appreciates the opportunity to submit testimony to the Senate Labor, Health and Human Services, Education, and Related Agencies (LHHS) Appropriations Subcommittee on fiscal year 2020 funding for the Centers for Disease Control and Prevention (CDC) and National Institutes of Health (NIH) programs addressing tropical infectious diseases and global health.

Tropical infectious diseases are by no means a new threat and they continue to pose significant challenges to the U.S. in our ongoing efforts abroad to improve public health and strengthen our relationships to the benefit of maintaining our Nation's security. While we understand the fiscal constraints we face and are sensitive to the job Congress must do, it is critical that the U.S. maintain robust funding in global health research and development (R&D) and that we not continue the current 'funding by crisis' cycle. The best examples of why this is needed can be seen in our recent response to the Zika and Ebola outbreaks. Responding to the Zika outbreak required billions of dollars of global investment that is still needed to support the development of a vaccine, coordinate mosquito control in at—risk areas, and monitor the spread of the disease.

We are again alarmed by the deep cuts proposed in the President's fiscal year 2020 budget, particularly for programs that support these efforts within CDC and NIH. We strongly advocate that the Subcommittee continue to support these programs by fully funding NIH and CDC in the fiscal year 2020 LHHS appropriations bill to protect the health of Americans and ensure continued U.S. investment in global health and tropical medicine research and development.

RETURN ON INVESTMENT OF U.S.-FUNDED RESEARCH

The programs at CDC and NIH are critical to advancing research and development for tropical medicine and global health. Both agencies employ leading experts who are at the forefront of science and provide partnerships that lead the U.S. to development of new tools to combat malaria, tuberculosis (TB), epidemic viruses, neglected tropical diseases (NTDs) and other infectious diseases. In addition to creating lifesaving new drugs and diagnostics to aid some of the poorest, most at-risk people in the world, this research provides jobs for American researchers and shines a light on the U.S. as a leader in health innovation. In 2015, 89 cents of $1 the U.S. Government invested in global health R&D was invested domestically within the U.S., supporting jobs for American researchers, scientists, and academics.[1]

TROPICAL DISEASE

Malaria: While we have seen tremendous success as a result of U.S. funded efforts to eliminate malaria, the disease remains a significant global health threat. Despite our ability to treat and prevent malaria, it is still one of the leading causes of death and disease worldwide. According to the latest estimates, approximately 3.2 billion people living in 106 countries and territories are at risk for malaria trans-

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[1] Global Health Technologies Coalition and Policy Cures Research. (2017). Return on Innovation: Why Global Health R&D is a Smart Investment for the United States. Retrieved from http://www.ghtcoalition.org/pdf/Return-on-innovation-Why-global-health-R–D-is-a-smart-investment-for-the-United-States.pdf.

mission.[2] Among these, malaria poses the most significant threat to poor women and children, but it is also a major threat to our military and other travelers to the tropics. In 2017, there were about 219 million new cases of malaria and an estimated 435,000 deaths.[3] Therefore, it is critical that the U.S. Government maintain strong investments in malaria efforts to ensure a steady decline in the number of those affected and outbreaks that reach the U.S. In 2015, at least 1 malaria case was reported in each of the 50 States with more than 200 reported in New York City and another almost 60 cases throughout the State of New York. There were over 100 cases in Maryland, Texas and California. Historical data shows that our U.S. investments in eliminating malaria in other countries has a direct correlation with the exposure in the U.S. A steep decline in malaria cases in Mexico since 1985 preceded an almost exact decline in the number of U.S. cases reported from Mexico over the same period of time. As a result of our collaborative efforts to fight malaria, mortality rates have fallen by 62 percent globally since 2002. Still, approximately every two minutes, a child needlessly dies of malaria.

Neglected Tropical Diseases: NTDs are a group of chronic parasitic and bacterial diseases that represent the most common infections of the world's poorest people. These diseases cause disfigurement, debilitation and extreme suffering—reducing cognitive development, stunting growth, and in some cases leading to death. As a result, NTDs severely limit the future earning potential of men, women, and children across the developing world resulting in further economic drain in already strained countries. These infections are considered a primary reason why the "bottom billion"—the 1.4 billion poorest people living below the poverty line—cannot escape poverty. While there is adequate treatment for some NTDs, there are many without adequate treatment or treatments that are not practical for low-resource settings. Tropical diseases, many of them neglected for decades, impact U.S. citizens working or traveling overseas, as well as our military personnel. Some diseases such as dengue fever, chikungunya, and Zika have even made their way to the U.S. with those like West Nile virus taking root here. Viruses are but a plane ride away from any point in the world, and U.S. citizens are inadequately protected and vulnerable.

THE CENTERS FOR DISEASE CONTROL AND PREVENTION

The Global Health Security Agenda: In partnership with other U.S. Government agencies, nations, international organizations, and public and private stakeholders, CDC announced a Global Health Security Agenda in 2014 to "accelerate progress toward a world safe and secure from infectious disease threats and to promote global health security as an international security priority." The Agenda focuses on preventing and reducing the likelihood of outbreaks, detecting threats early to save lives, and responding rapidly. The CDC's Center for Global Health and the National Center for Emerging & Zoonotic Infectious Diseases each play an important role in these efforts and must be supported through robust funding to carry out their duties.

The Center for Global Health:

Parasitic Diseases and Malaria: CDC's Division of Parasitic Diseases and Malaria (DPDM) works to protect the health of Americans and the global health community through evidence-based public health action. Specifically, DPDM aims to reduce death, illness, and disability from parasitic diseases in the United States, help to eliminate the global burden of malaria and targeted neglected tropical diseases (NTDs), and advance research to detect, prevent, and eliminate parasitic diseases.

DPDM appropriated funding has remained unchanged since 2004 with the exception of a modest increase in fiscal year 2018. With inflation, DPDM's "purchasing power" has diminished by at least 20 percent since 2004. Historically declining/flat funding coupled with inflation has eroded scientific core capacity. It's ability to address key gaps in new and improved disease detection and laboratory diagnostic tools needed to achieve malaria and neglected tropical disease elimination goals is diminished. Without increased funding it is highly likely that DPDM will have to reduce diagnostic services for parasitic diseases in the U.S., have longer turnaround times for serologic testing, face the inability to purchase/replace important diagnostic test equipment, could stop testing of vectors sent in from State and local health departments for parasitic diseases, and lack sufficient funds to purchase and stock artesunate and transport it to regional centers nationally for treatment of severe malaria. Artesunate is the only drug available to treat the hundreds of cases

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[2] Centers for Disease Control and Prevention. (2017). Malaria Facts. Retrieved from https://www.cdc.gov/malaria/about/facts.html.

[3] WHO Malaria Facts (2017). https://www.who.int/news-room/fact-sheets/detail/malaria.

of severe malaria seen each year in the United States, and it is available only through the CDC.

Further, CDC could be unable to continue to purchase and release the drugs currently only available through CDC, for treatment of life-threatening parasitic diseases. Current efforts to develop new diagnostic tests could be halted, leaving national and international public health laboratories with antiquated diagnostics methods. Ultimately, CDC's ability to respond quickly to outbreaks of parasitic infections could be limited and the technical support and staff it provides to efforts such as the President's Malaria Initiative and USAID's NTD program may need to be curtailed.

ASTMH encourages the subcommittee to continue to fund a comprehensive approach to malaria and parasitic disease prevention and treatment efforts through the Malaria and Parasitic Disease program. ASTMH continues to be alarmed that the budget request for this program has remained stagnant for over a decade. The lack of even modest increases for so long, with exception to fiscal year 2018, has effectively cut the program's budget year-over-year as overhead and research costs continue to rise. In order to provide for the continuation of the vital work of this program, we respectfully request $30 million for the CDC's Center for Global Health's Parasitic Disease and Malaria Program for fiscal year 2020.

The National Center for Emerging & Zoonotic Infectious Diseases (NCEZID) and its Vector Borne Disease Program (VBDP) funds essential surveillance and monitoring activities that protect the U.S. from deadly infections before they reach our borders and address the problems of tick and flea transmitted infections such as Lyme disease and a dozen other infections, including Zika and Ebola, that can be life-threatening within the U.S.

The CDC's Advanced Molecular Detection (AMD) program has brought next generation sequencing capabilities to the U.S. public health system, using DNA sequencing to address a wide range of infectious disease threats as well as antibiotic resistance. As a result, CDC has transformed how public health tracks and responds to these threats. Due to the rapid pace of technology change, we must ensure that the U.S. does not fall behind in the utilization of these emerging technologies.

ASTMH encourages the subcommittee to recognize the critical role that NCEZID and its VBDP and AMD program play in ongoing efforts to prepare for and fight tropical diseases emerging on U.S. soil, such as dengue, Chikungunya and now Zika. We also ask the subcommittee to encourages CDC to provide an update in the fiscal year 2021 congressional justification on challenges associated with ongoing technological advancements and a plan for how the AMD program will continue to maximize the potential of new technologies play in ongoing efforts to prepare for and fight tropical diseases emerging on U.S. soil, such as Dengue, Chikungunya and now Zika.

NATIONAL INSTITUTES OF HEALTH

Fogarty International Center (FIC): To protect the health and safety of Americans, the FIC has for three decades managed grant programs that develop scientific expertise in developing countries, ensuring there is local capacity to detect and address pandemics at their point of origin, contain outbreaks and minimize their impact. After all, we are all only as safe as our weakest link. More than 80 percent of FIC's approximately $54 million extramural grant making budget goes to U.S. institutions to support scientists' salaries and other costs. FIC programs fund over 500 projects involving about 100 U.S. universities. 100 percent of FIC grant awards in fiscal year 2016 involved U.S. researchers.[4]

Recent disease outbreaks such as Ebola, Zika, and Dengue have shown the importance of the Center's essential role in global infectious disease health research training and health system strengthening to help developing countries advance their own research, health solutions and tools. FIC has developed important partnerships in countries, including countries unfriendly to the U.S., to not only fight malaria, NTDs, and other infectious diseases, but also to have the capabilities to help the U.S. detect and treat infectious diseases before they travel to the United States thus protecting Americans here at home.

Ultimately, Fogarty plays a critical role in ensuring U.S. preparedness and our ability to protect our citizens against the next pandemic threat. Since 2008, Fogarty, in partnership with the Department of Homeland Security, has coordinated an effort to better predict and prevent the spread of infectious diseases in humans and ani-

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[4] National Institutes of Health. (2018). The John Edward Fogarty International Center: Fogarty at 50. Retrieved from https://www.fic.nih.gov/News/Publications/Documents/fogarty-international-center-overview.pdf.

mals, recently building out predictive risk maps to understand and forecast the spread of the Ebola and Zika virus epidemics. With these computational tools and data, policymakers can make informed decisions on how to respond to outbreaks.

ASTMH encourages the subcommittee to continue FIC's important work building relationships with scientists abroad to foster a stronger and more effective science workforce and health capacity on the ground, helping to detect infectious diseases and building the capacity to confront those diseases while improving the image of the U.S. though health diplomacy in their countries. Investments such as this are critical to protecting Americans from the next disease to cross our borders.

National Institute of Allergy and Infectious Diseases: NIAID is the lead institute for malaria and NTD research. In the past 2 years, NIAID has reported significant progress in addressing malaria, including the launch of a Phase 1 clinical trial for a new investigational drug to treat malaria and the recent development of low-cost diagnostic tests that can rapidly detect resistance of malaria to artemisinin, a first-line antimalarial drug. Resistance to artemisinin is a growing danger and one that we must be aggressively addressing. NIAID also helped lead accelerated trials of an Ebola vaccine and is working on important Zika research. Consistent investment is critical to achieve the drugs, diagnostics, and research capacity needed to control malaria, NTDs, Zika and Ebola.

ASTMH encourages the subcommittee to continue its investment in malaria and NTD research, including work in late-stage and translational research for NTDs, and to work with other agencies to foster research and ensure that basic discoveries are translated into much needed solutions.

CONCLUSION

The vast majority of infectious diseases do not emerge in the U.S., instead they thrive elsewhere often long before a catalytic event occurs that rapidly mobilizes the threat bringing it to the U.S. It is our lack of urgency and response to address these threats while they exist as remote tropical diseases that allows their spread and increases our domestic vulnerabilities. It is not a question of whether a new infectious disease outbreak will occur, it is a matter of when and what it will be. For this reason, Congress needs to support sustainable investments in U.S. global health R&D to increase our knowledge, understanding, and tools to confront infectious disease. ASTMH appreciates the opportunity to share its expertise and we hope you will provide the requested fiscal year 2020 resources to those programs identified above that will help improve the lives of Americans and the global poor.

[This statement was submitted by Chandy C. John, MD, MS, President, American Society of Tropical Medicine and Hygiene.]

PREPARED STATEMENT OF THE AMERICAN THORACIC SOCIETY

SUMMARY: FUNDING RECOMMENDATIONS

[In millions $]

National Institutes of Health	At least $41.6 billion
National Heart, Lung & Blood Institute	3.710
National Institute of Allergy & Infectious Disease	5.761
National Institute of Environmental Health Sciences	909
Fogarty International Center	82.9
National Institute of Nursing Research	173.4
Centers for Disease Control and Prevention	7.800
National Institute for Occupational Safety & Health	339.1
Asthma Programs	34
Div. of Tuberculosis Elimination	195.7
Global Tuberculosis (DGHT)	21
Office on Smoking and Health	310
National Sleep Awareness Roundtable (NSART)	1

The ATS's 16,000 members help prevent and fight respiratory disease through research, education, patient care and advocacy.

LUNG DISEASE IN AMERICA

Respiratory diseases are the third leading cause of death in the U.S., responsible for one of every seven deaths. Diseases affecting the respiratory (breathing) system include chronic obstructive pulmonary disease (COPD), lung cancer, influenza, sleep disordered breathing, pediatric lung disorders, tuberculosis, occupational lung disease, asthma, and critical illnesses such as sepsis.

NATIONAL INSTITUTES OF HEALTH

The NIH is the world's leader in groundbreaking biomedical health research into the prevention, treatment and cure of diseases such as lung cancer, COPD and asthma. The ATS thanks Congress for the $3 billion funding increase for NIH in fiscal year 2018. In order to continue to accelerate the development of life-saving cures and treatments and innovative prevention interventions, it is essential for Congress to continue providing robust, predictable funding increases across the full spectrum of NIH-supported research. The ATS is concerned that due to past reductions in Federal research funding, there remains a lack of opportunities for young investigators who are the future of scientific innovation. We ask the subcommittee to provide at least $41.6 billion in funding for the NIH in fiscal year 2020.

Despite the fact that respiratory disease is the third leading cause of death in the U.S., respiratory research is underfunded. The COPD death rate has doubled within the last 30 years and is still increasing, while the rates for the other top causes of death (heart disease, cancer and stroke) have decreased by over 50 percent. Despite the rising respiratory disease burden, research funding for the disease is disproportionally low relative to funding invested for the other three leading causes of death. In order to stem the devastating effects of respiratory disease, research funding must grow.

COPD

Chronic Obstructive Pulmonary Disease (COPD) is the fourth leading cause of death in the United States and the third leading cause of death worldwide, yet the disease remains relatively unknown to most Americans. CDC estimates that 12 million patients have COPD; an additional 12 million Americans are unaware that they have this life-threatening disease. COPD costs the economy almost $50 billion a year, including $29 billion in direct health expenditures and $29 billion in indirect costs such as lost wages.

The COPD National Action Plan, released in 2017, aims to expand surveillance and research on the disease, develop public health interventions and increase public awareness of the disease. The ATS urges Congress to provide NHLBI with $75 million in fiscal year 2020 for implementation of the COPD National Action Plan through the NHLBI and an additional $3 million for CDC to conduct COPD surveillance activities. We also urge CDC to include COPD-based questions to future CDC health surveys, including the National Health and Nutrition Evaluation Survey (NHANES), the Behavioral Risk Factor Surveillance System (BRFSS) and the National Health Information Survey (NHIS).

CENTERS FOR DISEASE CONTROL AND PREVENTION

In order to ensure that health promotion and chronic disease prevention are given top priority in Federal funding, the ATS supports a funding level for the Centers for Disease Control and Prevention (CDC) that enables it to carry out its prevention mission and ensure a translation of new research into effective State and local public health programs. We ask that the CDC budget be adjusted to reflect increased needs in chronic disease prevention, infectious disease control, including TB control and occupational safety and health research and training. The ATS recommends a funding level of $7.800 billion for the CDC in fiscal year 2020.

ANTIBIOTIC RESISTANCE

In November 2018, the Journal of Infection Control and Hospital Epidemiology reported that as many as 162,044 people die in the U.S. each year as a result of antimicrobial resistant infections, 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
—$22.75 million for the National Healthcare Safety Network (NHSN)
—$32.5 million for the Advanced Molecular Detection (AMD) Initiative

We urge the committee to provide $5.761 billion for the National Institutes of Allergy and Infectious Disease (NIAID) to spur research into rapid new diagnostics, new treatments and other activities and $750 million for the Biomedical Advanced

Research and Development Authority (BARDA) to support antimicrobial research and development.

TOBACCO CONTROL

Tobacco use is the leading preventable cause of death in the U.S., responsible for one in five deaths annually. Tobacco cessation and prevention activities are among the most effective and cost-effective investments in disease prevention. The CDC's Office on Smoking and Health (OSH) is the lead Federal program for tobacco prevention and control and created the "Tips from Former Smokers" Campaign, which has prompted hundreds of thousands of smokers to call 1–800–QUIT–NOW or visit smokefree.gov for assistance in quitting—with even more smokers making quit attempts on their own or with the assistance of their physicians. The ATS recommends a total funding level of $310 million for the Office of Smoking and Health in fiscal year 2020.

ASTHMA

Asthma is a significant public health problem in the U.S. Approximately 26 million Americans currently have asthma. In 2016, 3,274 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 provide $34 million in fiscal year 2020 for CDC's National Asthma Control Program.

TUBERCULOSIS

Tuberculosis (TB) is the leading global infectious disease killer, ahead of HIV/AIDS, claiming 1.6 million lives each year. In the U.S., every State reports cases of TB annually and in 2018, twenty-two States reported TB increases. The CDC has identified drug resistant TB as a serious public health threat to the U.S. Drug-resistant TB strains pose 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.

CDC's work on global TB is underfunded and is mostly transferred in through other accounts. Increasing CDC's Division of Global HIV and TB funding to $21 million, would allow the agency to use its unique technical expertise to address the nexus between the global TB epidemic and the incidence of TB in the U.S. We request that this funding be provided directly through a new budget line for CDC's work on global TB.

The ATS recommends a funding level of $195.7 million in fiscal year 2020 for CDC's Division of TB Elimination. and new line-item funding of $21 million for CDC's Global TB program through the Center for Global Health. We urge the NIH to expand research to develop new tools to address TB. Additionally, in recognition of the unique public health threat posed by drug resistant TB, the ATS urges BARDA to support research and development into new drug-resistant TB diagnostic, treatment and prevention tools.

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 2020 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).

PEDIATRIC LUNG DISEASE

The ATS is pleased to report that infant death rates for various lung diseases have declined for the past 10 years. Many of the precursors of adult respiratory disease start in childhood. For instance, many children with respiratory illness grow into adults with COPD. It is estimated that 6.1 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.

RESEARCHING AND PREVENTING OCCUPATIONAL LUNG DISEASE

As Congress considers funding priorities for fiscal year 2020, 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.

LEGISLATIVE RIDERS

We urge the Senate to refrain from considering legislative riders in this and all appropriations bills. By refraining from considering legislative riders, Congress can more swiftly complete its constitutional obligation for completing appropriations bills in a timely manner.

[This statement was submitted by James Beck, MD, President, American Thoracic Society.]

PREPARED STATEMENT OF THE ANIMAL WELFARE INSTITUTE

The Animal Welfare Institute appreciates the opportunity to submit testimony on fiscal year 2020 spending priorities for the U.S. Department of Health and Human Services.

PROTECTING ANIMALS WITH SHELTER (SECTION 12502 OF THE FARM BILL)

When there is violence in the home, it can be directed at everyone-spouse or partners, children, elderly family members, and companion animals. Abusers are well aware of the bond between their victims and their pets. They exploit that bond to frighten, control, manipulate, and even “punish” their human victims.

Unfortunately, few domestic violence survivors have access to shelters that can protect them and their pet; in fact, large numbers delay escaping out of fear for the safety of the pets left behind. Several surveys bear the grim statistics:

—As many as 48 percent of the battered women reported they had delayed leaving a dangerous situation out of concern for their companion animals’ safety.
—Between 49 percent and 86 percent reported that their pets had been threatened, harmed, or killed by their partners.
—85 percent of domestic violence shelters indicated that women coming to their facilities spoke of incidents of pet abuse.

Congress has wisely sought to address this shortage of resources. Section 12502 of Public Law 115–334, the Agriculture Improvement Act of 2018, authorizes a grant program to provide emergency and transitional shelter and housing options for domestic violence survivors with companion animals. It is urgent that Congress now appropriate the authorized funding and direct the agencies involved to take all necessary steps to implement the program. If shelters and other service providers can help domestic violence survivors find a safe place for their companion animals, they will be better able be to bring everyone to safety. The PAWS provision will greatly increase their capacity to meet these critical needs.

Requested Report Language: The Committee directs the Secretary of Health and Human Services to enter into consultations with the Secretary of Agriculture as soon as possible, and enter into any memoranda of understanding as directed, in order to establish during fiscal year 2020 the requirements for grant application and execution under Section 12502 of Public Law 115–334, the Agriculture Improvement Act of 2018, to provide emergency and transitional shelter and housing options for domestic violence survivors with companion animals.

[This statement was submitted by Nancy Blaney, Director, Government Affairs.]

PREPARED STATEMENT OF KATHERINE ARLINE

Thank you for the opportunity to submit testimony related to a matter that is close to my heart. My name is Katherine Arline, and I work for a rare-cancer focused biotech company called SHEPHERD Therapeutics. We may be the only pan rare-cancer focused company in the world, and that is significant for reasons I'll discuss below. More important, though, is the reason I work at SHEPHERD. Two years ago, when he was 36, my fiancé had a seizure one night as we were preparing dinner. With no prior warning, we entered a whirlwind of MRIs, doctors, and varying potential diagnoses. But what I remember most of that first evening is that while he slept, I sat staring at his bed and knowing that the future we had dreamed of was lost, or at the very least changed forever.

We are fortunate to live in Boston and have access to outstanding hospitals conducting research into his form of cancer, oligodendroglioma. He was lucky to have an established treatment protocol—albeit decades old—and is doing well now. But when his tumor starts growing again, there will be little to offer him beyond surgery that will change his life permanently, and therapies which have not been extensively tested on his cancer.

Everything changed after that day. The realization of how few options there are for cancer patients like my fiancé, drove me to change my career and life and come to work for SHEPHERD. SHEPHERD was founded by another patient, David Hysong, who at age 27, while undergoing Navy SEAL selection training, collapsed and, like my fiancé, was diagnosed with a rare cancer, this one called adenoid cystic carcinoma. As I did, David quickly discovered that "modern" medicine is a myth for far too many patients. David had his tumor surgically removed. But when his cancer returns, as it is likely to do, he may have no choices beyond more surgery, radiation, chemotherapy that is ineffective for his cancer, and other treatments which have not been proven to work for his cancer.

Since I joined SHEPHERD, I have led a team conducting research about rare cancers, including their forms, incidence, disparities surrounding diagnosis and care, challenges of treatment, and outcomes. We had to undertake this work because this type of information is lacking for rare cancers. To complete this work, we reviewed government and public databases, scoured cancer publications on PubMed, talked with researchers, and tracked information from patient foundations. Initially, our goal was to find the cancers that had sufficient basic science and demographic data to make them ready for drug development and for clinical trials. We soon learned just how many rare cancer patients are faced with vanishingly small odds of receiving a modern standard of care during the course of their disease. We learned that "rare" is the wrong word to describe a diagnosis that almost 1 in 3 new cancer patients will receive this year.

At that point, our research took on another purpose entirely. We aimed to use the information we found to help the government and the public understand that "rare isn't rare"—and that giving patients a highly specific diagnosis, defined by molecular diagnostics and supported by adequate basic science, patient foundations, and organizations like SHEPHERD can turn a diagnosis into a superpower, and not a death sentence.

From our research, we have learned that 380 out of the 400 forms of cancer we have identified meet the most conservative estimate of what constitutes a rare cancer, the American Cancer Society's metric of fewer than 6 new diagnoses per 100,000 people per year. That's 95 percent of all forms of cancer, which collectively will afflict over 550,000 new patients this year. As additional genetic tests lead to further subsetting of large cancers into distinct forms, more and more cancers will become rare—and potentially suffer from the disparities I outline below.

A number of special populations face additional burdens from rare cancers. While it is well known that all pediatric cancers are rare, many may not realize that minorities, service members, and veterans are disproportionately faced with rare cancer diagnoses. In particular, those who have served our country in uniform are disproportionately affected by over 60 forms of cancer. Almost 70 percent of those cancers are rare, and only 25 of them have an FDA approved targeted therapy. Many of those cancers are potentially caused by service-related exposures such as asbestos, burn pits, radiation, and Agent Orange. Tragically, according to a National Academy of Sciences study, the children of veterans who were exposed to Agent Orange may also have an increased risk of certain cancers, like AML.

In addition, African Americans, Asian Americans, Hispanic Americans, American Indians, Alaska Natives, and underserved Caucasians are more likely than the general population to have a higher incidence and death rate for certain types of rare cancer. Rare cancers in particular occur more frequently among Hispanics and Asians and Pacific Islanders when compared with non-Hispanic blacks and whites. Moreover, these populations frequently suffer from worse outcomes and shorter survival times. African American cancer patients in particular have a lower 5-year survival rate than white patients.

Clinical trials are in some cases a cancer patient's best option for treatment. However, rare cancer patients face disparities in access there as well. Our analysis of all clinical trials between 2012 and 2016 showed that 74.89 percent of all trials did not include even one rare cancer. Only around 13 percent of all rare cancers were specifically named as a focus of a phase 3 clinical trial in those 5 years. More than 4 times as much money in that timeframe was spent on non-rare cancer trials than on trials which included a rare cancer. For minorities, these discrepancies are amplified, as minorities are less likely than Caucasians to be included in clinical trials, which can lead to underrepresentation of key biological variables that make drugs less effective among those populations.

And while many new drugs are arriving on the market for rare cancer patients, it is still the case that the vast majority of new cancer patients—over 80%—who lack even one FDA-approved targeted therapy for their cancer are rare cancer patients. What is the significance of a targeted therapy? Unlike radiation and chemotherapy, targeted therapies can affect cancer cells more specifically than older forms of therapy, which means patients may experience fewer side effects. Targeted therapies can attack the causes of a cancer by silencing overactive genes, boosting suppressed genes, or stimulating an immune response. In a word, targeted therapies are the future. The good news is that for many cancer patients, they are also the present, and myriad success stories exist of remarkable improvements in health and long-term responses to targeted therapies as well as combinations of targeted therapies with traditional radiation and chemotherapy. Unfortunately, and as ever, rare cancer patients suffer from disparities in access to these newer treatments. As of February 2019, 182 cancers lacked a FDA-approved targeted therapy. 181 of them were rare cancers. That means that in 2019 almost 200,000 new rare cancer patients will face their diagnosis without a modern treatment.

Chemotherapy and radiation remain important tools to fight cancer in the absence of targeted therapies, and in conjunction with them. But all therapies are best used in the context of decisionmaking informed by evidence provided by clinical trials. Without an approved standard of care, however, clinicians treating rare cancers frequently default to radiation and chemotherapy, even without a data suggesting that such a treatment protocol will work for a given cancer.

Unfortunately, off-label and compassionate use of targeted therapies are not a solution for this problem. Without coverage from insurance, rare cancer patients who are forced to use off-label drugs, because there are no good options for their cancer, can face bankruptcy due to the cost of paying for drugs out of their pocket. The cost of travel to clinical trials, when they are available, contributes to this financial burden.

The reasons we find ourselves in this situation are myriad, but fundamentally they come down to money. Clinical trials are expensive to run, and pharmaceutical companies are unlikely to choose to run a clinical trial in a small indication with few patients when a drug will work for a large population, even if that population already has dozens of drugs available for use, and even if that drug is a "me too" therapy which provides little benefit over the current standard of care. Most companies assess the numbers for rare cancers and decide that the cost of drug development cannot be justified by the potential market for a rare cancer like adenoid cystic carcinoma, which has around 1,200 new patients a year.

Fortunately, in the last few years, the FDA has encouraged new trial designs that allow trials to be run which target the molecular drivers of a cancer, allowing all patients whose tumors exhibit that trait to potentially be included in the trial. This is science at its best. In November 2018, the effectiveness of this approach was proven when Loxo Pharmaceuticals received approval for larotrectinib, a therapy for solid tumors with NTRK gene fusions. Those fusions occur in just 1 percent of cancers, but because Loxo was considering the entire cancer patient population, the drug was economically feasible to develop. This drug was approved on the basis of results from the first 55 patients enrolled in their trial and achieved a stunning overall response rate of 75 percent. Compared to the response rates at time of FDA approval of other oncology drugs, such as 10 percent for sorafenic, 28 percent for tivozanib, and 26 to 52 percent for PD1 inhibitors, larotrectinib represented a breakthrough in therapeutic benefit. This is the power of targeted therapies, used intelligently, for the benefit of all patients.

This is what the future looks like. But to take all patients into that future, data is required, and data starts with patients even being offered the option to have their tumors analyzed, to understand what actual genetic causes lay behind their cancer, and to understand which clinical trials and molecularly targeted therapies may be appropriate for them. Last year, CMS acted to ensure that Medicare and Medicaid patients whose cancer recurs after treatment receive molecular diagnostics. However, cancers which are newly diagnosed are still infrequently typed molecularly; when molecular testing is conducted, it may be paid for by the hospital or by donors rather than by an insurance carrier—thus magnifying disparities in care between those who are able to access well-funded care centers and those who are not. This can contribute to the use of therapies that are ineffective or inappropriate for a given patient.

Data from molecular typing can end up, with patients' permission, as part of research studies, and some of those studies share their data in publicly available sources. At the most fundamental level, that raw data is required to drive scientific understanding of what causes a disease, the types of therapies which may work on it, and the ability to recruit sufficient numbers of patients for molecularly-targeted clinical trials like the one Loxo was able to run. Even when tumor samples are obtained, the collection frequently occurs after a first round of treatment rather than at the time of diagnosis. Having data only from recurrent disease can make it more difficult for researchers and drug developers to understand what is truly causing a cancer, since mutations that occur after treatment in metastatic tumors look and act differently from the original disease. This underscores the need for frontline diagnostics.

Unsurprisingly, there are significant data gaps for rare cancers. Research we presented at the American Association of Cancer Researchers on April 2, 2019 showed that over 120 cancers, all rare, had no datasets in the Gene Expression Omnibus (GEO) repository, one of the most significant genomic data repositories in the world. Those rare cancers which were included had, on average, only 1 dataset per cancer. That amount of data is inadequate to power the most promising data analytic techniques currently available. In contrast, non-rare cancers, on average, had over 22 datasets per cancer, composed of hundreds or thousands of patients in aggregate. Our analysis showed a statistically significant correlation between the availability of GEO datasets and the availability of an FDA-approved targeted therapy for a given cancer. Cancers without a GEO dataset were 6.8 times less likely to have a targeted therapy than those with even one publicly available dataset.

Why have we arrived at this situation? Are rare cancers harder to research, diagnose, and treat? In most cases, we believe the answer is no. What is lacking is the funding, research, and amount of data sufficient to allow new therapies to be developed and tested in the clinic. That, fundamentally, is an economic problem, and it starts with spending in the Federal Government, since NIH is a highly significant underwriter of basic and translational research.

As a government, as corporations, and as a people, we will save the lives we choose to save. Every day, new research is paving the way for scientific advances that will make cancer a chronic or even a curable condition. Rather than family members watching helplessly as their loved ones suffer and die, we can empower them to understand their disease and to receive the best standard of care possible. But unless a commitment is made to share these advances with all new cancer patients, we risk widening the gap between those "lucky" enough to be diagnosed with a common cancer and those unlucky enough to be diagnosed in the wrong place, in the wrong way, and with the wrong disease.

That is why we are asking you to make a commitment to treat all cancer patients as equally deserving of dignity, and of a chance at life. That path starts with the commitment of the United States Government, of the NIH, NCI, NCATS, and the other agencies that work tirelessly to advance basic and translational science. Before more money is allocated for common cancers with 99 percent cure rates, we ask that you consider the patients with no modern standard of care, no access to clinical trials, no Federal spending for their disease—and no hope.

Please stand with us and make a pledge to double Federal spending on rare cancers, to incentivize the coverage of frontline molecular diagnostics for all newly diagnosed patients, and to prioritize research, data sharing, and translational development for cancers that lack an FDA approved targeted therapy. Behind the statistics are over half a million Americans who at this moment do not know that during the course of this year they will be diagnosed with a cancer for which there is frequently no treatment beyond what their parents or even their grandparents would have been offered. Science sees no second class citizens, only patients in need of help. We ask the United States Government to do the same. Please commit to ensuring that as a country, we will no longer allow any cancer patients to be overlooked, forgotten, or left behind.

PREPARED STATEMENT OF THE ARTHRITIS FOUNDATION

On behalf of the 54 million adults and 300,000 children living with doctor-diagnosed arthritis in the United States, the Arthritis Foundation thanks Chairman Blunt and Ranking Member Murray for the opportunity to provide written testimony to the Appropriations Subcommittee on Labor, Health and Human Services (HHS), and Education and Related Agencies for fiscal year 2020. We respectfully request $16 million for the Centers for Disease Control and Prevention (CDC) Arthritis Program as well as sufficient funding for the National Institutes of Health (NIH) broadly, with a specific request of $673 million for the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) in fiscal year 2020.

Arthritis affects 1 in 4 Americans and is the leading cause of disability in the United States, according to CDC. It limits the daily activities of over 23 million Americans and causes work limitations for 40 percent of the people with the disease. This translates to over $300 billion a year in direct and indirect costs. There is no cure for arthritis, and for some forms of arthritis like OA, there is no disease-modifying pharmaceutical therapy. Research is critical to build towards a cure, develop better treatments with fewer severe side effects, and identify biomarkers and therapies for types of arthritis for which none exist. A strong investment in public health research and programs is essential to making breakthroughs in treatments, finding a cure for arthritis, and for delivering those breakthroughs to the people who suffer from this debilitating disease.

CENTERS FOR DISEASE CONTROL AND PREVENTION ARTHRITIS PROGRAM

The CDC Arthritis Program is the only Federal program dedicated solely to arthritis. Today, the program provides grants to 13 States to support evidence-based disease management programs. The program aims to connect all Americans with arthritis to resources to help them manage their disease. Evidence-based programs like Walk With Ease 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.

A member of the Arthritis Foundation staff had the opportunity to meet with two Walk With Ease classes in the Shreveport, Louisiana area in December 2018. The tremendous impact of the program on these participants' lives cannot be overstated. They described the exercises and activities as the things that keep them going: "Before I started the program I couldn't really walk, and now that I do the program I am walking all over town." When participants were asked to share their greatest challenges with living with arthritis or other musculoskeletal pain, the value of the program came up—unprompted—as the "reason to get out of bed."

Given the high prevalence and severity of this disease, the Arthritis Program is woefully under-funded compared to the investment in other chronic diseases. From a historical perspective, funding for the program was cut by 25 percent in fiscal year 2015, bringing the fiscal year 2015 total down from $13 million to $9.5 million. As a result, program staff had to cut program activities between 10 and 50 percent, with some eliminations, and were unable to make new investments in arthritis programs. While $1.5 million was restored in fiscal year 2016, the Arthritis Program is still not operating at its funding level of $13.3 million during fiscal year 2010. Combined with previous flat funding, the program has lost millions of dollars in purchasing power over the last 8 fiscal years.

The latest data from the CDC Arthritis Program estimates that arthritis now affects 20 percent of the population in 48 of 50 States, bolstering the need for all 50 States to receive funding from the program. While this is a long-term goal, a critical first step is to increase funding in fiscal year 2020 by $5 million (for a total of $16 million) so the program can continue its current level of operations and begin to expand into additional States. With a $5 million increase, the Arthritis Program could:

—Continue important data collection on arthritis prevalence and public health impacts;
—Support up to six (6) new State programs for a total of 19 States;
—Increase support of national dissemination of evidence-based programs; and
—Create an Arthritis Management Network that would fund up to three (3) projects to develop and evaluate interventions that can better understand the impact of comorbidities and improve existing self-management and physical activity among adults with arthritis.

NATIONAL INSTITUTES OF HEALTH

As previously stated, there is no cure for arthritis, and for some forms of the disease, no disease-modifying therapeutics. Even for autoimmune forms of the disease like RA, biologic medications—which have revolutionized treatment by halting the progress of disease in many patients—have severe side effects. There is also no "gold standard" diagnostic for many forms of arthritis like RA and juvenile arthritis, and therefore it can take a long time to diagnose these diseases. It is not uncommon for children to go months without an official diagnosis, which can delay the start of critical treatment. Research is the key to identifying better diagnostics and better treatments, so that people have access to treatments early in their disease, ensuring a higher quality of life and better health outcomes.

The National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) is one of the primary NIH Institutes that supports arthritis research. Unfortunately, funding for NIAMS has not kept pace with inflation over the last several fiscal years. In fact, funding for the NIAMS research agenda has be cut significantly. As a percentage of the total appropriation for all NIH centers and institutes, NIAMS's share of funding declined to 1.55 percent in the last fiscal year from a high of 1.73 percent in fiscal year 2010. Perhaps more urgently, the funding level for NIAMS does not adequately reflect the disease burden within its purview. Osteoarthritis alone impacts tens of millions of people, costing hundreds of millions of dollars annually, and has no disease-modifying therapeutic. We urge you to address this funding disparity by appropriating $673 million for NIAMS in fiscal year 2020.

We thank the Subcommittee for its commitment to the health and wellbeing of all Americans. As you write the fiscal year 2020 Labor-HHS-Education appropriations bill, we hope you will fund the CDC Arthritis Program at $16 million and provide $673 million for NIAMS to continue investments in improving the lives of people with arthritis. Please contact Vincent Pacileo, Director of Federal Affairs, at vpacileo@arthritis.org, with any questions.

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 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: $465.8 million for Core Infectious Diseases including $200 million for the Antibiotic Resistance Solutions Initiative, $22.75 million for the National Healthcare Safety Network (NHSN), and $32.5 million for the Advanced Molecular Detection (AMD) Initiative. Additionally, we request $36 million for HAI research activity conducted by the Agency for Healthcare Research and Quality (AHRQ) and $5.8 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 31 hospitalized patients has at least one HAI at any given time. Annually that means 687,000 patients will contract a HAI with nearly 72,000 dying as a result. An increasing number of these infections are untreatable due to resistance to our current arsenal of antibiotics. Without immediate intervention, antibiotic resistance can make minor infections become life-threatening and put our ability to perform surgical procedures at risk. The CDC conservatively estimates that in the United States 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 $465.8 million for Core Infectious Diseases for fiscal year 2020, 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 to quickly translate surveillance and research activities into policy and public health practice. 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 city health departments, and Puerto Rico. By working with State and local health departments the AR Solutions Initiative is protecting life-saving antibiotics and the future of medical innovation from the threat of antibiotic resistance. The program also supports the Antibiotic Resistance Lab Network, which provides the infrastructure and lab capacity for seven regional labs to detect resistant organisms. Through these labs, CDC is able to identify pathogens which are resistant to all or most antibiotics. For instance, in 2017 lab tests uncovered unusual resistance more than 200 times in “nightmare bacteria” alone.

We urge you to support $22.75 million for CDC’s National Healthcare Safety Network (NHSN). 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 Clostridioides difficile infections. This funding enables the CDC to provide technical support to more than 22,000 healthcare facilities, which represents 65,000 users across the continuum of care. These funds will allow 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, critical user support, and provide innovative HAI prevention approaches.

We urge your continued support of $32.5 million for the Advanced Molecular Detection (AMD) Initiative in bioinformatics and genomics, which allows CDC to more quickly determine where emerging diseases come from, whether microbes are resistant, and how microbes are moving through a population. This initiative is critical because it strengthens CDC’s epidemiologic and laboratory expertise to effectively guide public health action.

AGENCY FOR HEALTHCARE RESEARCH AND QUALITY

We request your support of $36 million for AHRQ’s HAI research activity. This funding supports projects to advance the science of HAI prevention, develop more effective approaches for reducing HAIs, and help clinicians apply proven methods to prevent HAIs on the front lines of care. The projects funded by AHRQ’s HAI Program accelerate the implementation of evidence-based methods to reduce HAIs in acute care hospitals as well as ambulatory and long-term care settings. Distinct from the research funded through NIH, AHRQ funds critical research focused on improving the safety and quality of the U.S. healthcare system.

NATIONAL INSTITUTES OF HEALTH/NATIONAL INSTITUTE OF ALLERGY AND INFECTIOUS DISEASES

SHEA and APIC support $5.8 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 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 as well as 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 nearly 16,000 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.

[This statement was submitted by Lisa Tomlinson, Vice President, Government Affairs and Practice Guidance, APIC and Lynne Jones Batshon, Director, Policy and Practice, SHEA.]

PREPARED STATEMENT OF THE ASSOCIATION FOR PSYCHOLOGICAL SCIENCE

APS RECOMMENDATIONS FOR FISCAL YEAR 2020 APPROPRIATIONS

—As a member of the Ad Hoc Group for Medical Research, APS recommends at least $41.6 billion for NIH in fiscal year 2020. This would be a $2.5 billion increase over NIH's program level funding in fiscal year 2019. This funding level would allow for meaningful growth above inflation in the base budget that would expand NIH's capacity to support promising science in all disciplines beyond the directed funding included in the 21st Century Cures Act. It also would ensure that funding from the Innovation Account established in the 21st Century Cures Act would supplement the agency's base budget, as intended, through dedicated funding for specific programs.

—APS asks the Committee to continue to engage with NIH regarding NIH's proposed redefinition of clinical trials to include basic research. The Committee included very direct report language in the fiscal year 2018 Omnibus directing NIH to "delay enforcement of the new policy" and "consult with the basic research community to determine reporting standards best suited to this kind of research." However, NIH is choosing to ignore the intent of the Committee, and is continuing to move forward with a new policy that will reclassify a significant amount of basic research as a clinical trial and will subject this research to the added regulations and cost of clinical trials. APS is working on a compromise that would use NIH's new funding stream, basic science experimental studies involving humans (BESH), but will not require applications to go through clinicaltrials.gov or be called a clinical trial.

—Behavior is involved in the development, treatment, or prevention of virtually every public health issue facing this Nation, including opioid addiction, heart disease, cancer, diabetes, mental illness, AIDS, violence, traumatic brain injury, and alcoholism. APS asks Congress to urge NIH to establish an advisory panel to review and recommend programs and structures that will result in a stronger basic, applied, and clinical behavioral science research and training enterprise at NIH in recognition of the central role of behavior in health.

—APS asks the Committee to encourage the National Institute of Mental Health to diversify its research portfolio to establish a better balance between neuroscience and basic and applied behavioral research to increase the development of more effective treatments for reducing the urgent public health and economic burdens resulting from the prevalence of these conditions.

—APS urges the Committee to monitor and ensure that NIH is complying with Federal statute (Title 42 of the US Code, Subchapter III; Part B, Subsection 284A) that all NIH Directors Advisory Councils have at least two representatives from the fields of public health and the behavioral or social sciences.

Mr. Chairman and Members of the Subcommittee, thank you for the opportunity to provide testimony as you consider funding priorities for fiscal year 2020. I am Sarah Brookhart, Executive Director of the Association for Psychological Science (APS).

APS is a nonprofit organization dedicated to the advancement of scientific psychology nationally and internationally. APS's 35,000 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 study how children grow, learn, and develop; they use brain imaging to explore thinking and memory and other aspects of cognition; they research ways to manage debilitating chronic conditions such as diabetes and arthritis as well as depression and other mental disorders; they examine how genes and the environment influence behavioral traits such as aggression and anxiety; and they address the behavioral aspects of smoking and substance abuse.

RECOGNIZING THE LEADERSHIP OF THE SUBCOMMITTEE

Mr. Chairman, APS recognizes and appreciates your leadership and the leadership of this Subcommittee in supporting public health research. We applaud the Committee's commitment to improving health through science and to allocating increased funding to these programs during periods of fiscal austerity so that the pace of scientific discovery needed to address the Nation's health needs remain vital. We are particularly grateful for your leadership in securing a $2 billion increase for the NIH in fiscal year 2019. While many of these funds are set aside for specific projects, we appreciate your vision in ensuring that every Institute and Center has growth above fiscal year 2018 levels. This will help expand the agency's capacity to make progress across the full spectrum of scientific opportunity and increase funding available for investigator initiated scientific research. We do, however, share the concern of many groups that the increasing trend to earmark NIH funding is troublesome.

FUNDING FOR THE NATIONAL INSTITUTES OF HEALTH AND POLICY ISSUES

As previously noted, APS recommends an fiscal year 2020 funding level of $41.6 billion for NIH, which would enable real growth over health research inflation as an important step to ensuring stability in the Nation's research capacity over the long term. Securing a reliable, robust budget trajectory for NIH will be important in positioning the agency—and the public which relies on it—to capitalize on the full range of health research being conducted in the biomedical, behavioral, social, and population-based sciences. The Administration's request of $34.4 billion in fiscal year 2020, translating to approximately a $4.7 billion cut, is reckless and shortsighted. Cuts to NIH would affect every American, including patients, their families, researchers, and communities where NIH investment spurs economic growth. APS, and the entire health research community, strongly oppose the Administration's proposal.

In addition to funding priorities, APS is concerned about several policy issues at the NIH.

Clinical Trials Definition: APS continues to be concerned that NIH is moving forward with the implementation of a new definition of clinical trials that encompasses significant amounts of basic research with humans. This NIH action ignores over 3,500 comments in opposition to this change, the opposition of 35 current and former members of NIH advisory councils (as conveyed in a letter to Director Collins), and concerns expressed by the Committee in its fiscal year 2018 Conference report language. Basic research by definition is aimed at furthering knowledge about underlying processes and conditions involved in a particular phenomenon. Clinical trials are explicitly designed to test the safety and effectiveness of treatment or prevention interventions on health outcomes. The new definition of clinical trial encompasses basic research studies which are not traditionally considered to be a clinical trial by NIH or by the scientific community. In doing so, NIH is subjecting entire areas of basic research to inappropriate and unnecessary requirements that would add significantly to the cost and time of each project and would also create a significant economic burden for university and government review and training programs. To help reverse this policy change, we urge the following fiscal year 2020 report language in the NIH Office of the Director:

> *Clinical Trials Policy*.—The Committee continues to be concerned that NIH is moving forward with the implementation of a new definition of clinical trials that encompasses significant amounts of basic research with humans. This NIH action ignores over 3,500 comments in opposition to this change, the disapproval of 35 current and former members of NIH advisory councils, and concerns expressed by the Committee in its fiscal year 2018 Conference report language. Contrary to NIH claims, this action is not suggested or required by the 21st Century Cures Act. While the Committee supports efforts to increase transparency and improve oversight of clinical trials, these policies are unnecessary to meet those goals, given that viable and cost effective alternatives exist for basic research with humans. These policies subject basic research with humans to unnecessary oversight, regulations, and requirements at the Federal and institutional levels that are burdensome, irrelevant, and costly for scientific research. The Committee urges NIH to not classify basic research as clinical trials and to work with basic human subjects researchers to develop appropriate policies for NIH-funded basic research.

Behavioral Science at NIH: The National Institute of Health (NIH) mission is to "seek fundamental knowledge about the nature and behavior of living systems and the application of that knowledge to enhance health, lengthen life, and reduce illness and disability." However, increasingly, the Association for Psychological Science has concerns about the status of behavioral science at NIH; specifically, the continued disparity between the central role of behavior in all areas of health and the low level of support for basic and applied behavioral science research and training. APS therefore requests that the following language be included in the fiscal year 2020 Labor-HHS Appropriations Report directing the Director of NIH to convene a special advisory panel of behavioral scientists and other community experts to complete an assessment providing recommendations on how to better integrate and realize the benefits to overall health from behavioral research at NIH:

> *Behavioral Research*.—The Committee is concerned that the weak NIH commitment to behavioral science research and training is not consistent with the important connections between behavior and health. Most of the leading public health issues facing our Nation-including cancer, addiction, heart disease, mental illness, diabetes, violence, and AIDS—are rooted in individual and social behavior, yet behavioral science is decentralized across NIH's institutes and the Office of the Director limits guidance and authority to manage and direct this important research. The Committee therefore requests that the Director convene a special advisory panel of behavioral scientists and other community experts to complete an assessment providing recommendations on how to better integrate and realize the benefits to overall health from behavioral research at NIH. The Committee requests that this assessment be finalized before the end of fiscal year 2020 and be submitted to Congress.

Improving the Treatment of Mental Illness: APS continues to be concerned about the inadequate recognition at NIH of the role of behavior in health, as reflected in the absence of behavioral science among the priorities at many institutes. Specifically, we share the concern expressed by the National Institute of Mental Health (NIMH) National Advisory Mental Health Council that over the past decade the NIMH research portfolio has increasingly become focused on basic and molecular neuroscience research at the expense of research focused on finding ways to ease the burden of those currently suffering from devastating mental conditions. In fact, in January 2018, the NIMH Director noted that over the last 10 years, this policy shift has resulted in a 50 percent decline in applications for applied and translational science. This decline illustrates the signal NIMH has sent to the research community that basic and molecular neuroscience grants are the priority over applied behavioral science. APS believes that the individual, social, and economic burdens of mental illness will not begin to be alleviated until there is a more comprehensive research approach. The NIMH mission to support research and training to reduce the public health burden of mental illness has never been more urgent; it is imperative that the Institute employ the full range of scientific resources that are available in pursuit of its mission. Therefore, APS urges the Committee to include the following language instructing 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 continues to be concerned that over the past decade the NIMH research portfolio has increas-

> ingly become focused on basic neuroscience research at the expense of a more balanced portfolio that would also fund basic and applied behavioral and psychosocial research focused on finding ways to meet the public health mission to ease the burden of those affected today. This NIMH policy shift has led to a 50 percent decline in applied and translational applications in this 10 year period as NIMH has signaled to the research community a prioritization of basic neuroscience research. The Committee urges NIMH to take steps to diversify its research portfolio to better balance between neuroscience and basic and applied behavioral and psychosocial research and requests a report on actions taken and planned to meet this goal.

NIH Advisory Committees: Congress recognized the important role that behavioral and social science plays in addressing the Nation's health needs by including a requirement in Section 284 of Title 42, Subchapter III of the US Code that membership of each NIH Advisory Committee should include "not less than two individuals who are leaders in the fields of public health and the behavioral or social sciences" relevant to the activities of the national research institute for which the advisory council is established. While there are some Institutes, such as the National Institute of Mental Health, that work diligently to adhere to this Federal requirement, other institutes are not in compliance. Therefore, APS requests the following language be included in the fiscal year 2020 Labor-HHS report to address this issue:

> *Directors Advisory Committees*.—The Committee is concerned that despite the legal requirement of Federal statute (Title 42 of the US Code, Subchapter III; Part B, Subsection 284A) that all NIH Directors Advisory Councils have at least two representatives from the fields of public health and the behavioral or social sciences, recent reviews of the membership of Institute Directors Advisory Councils reveal that not all institutes are in compliance with this requirement. The Committee urges compliance with this statute and requests a report on the fields of public health and behavioral and social sciences that are represented on each advisory committee and measures planned and completed to comply with the requirements of this statute.

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 wellbeing of our Nation, adequate funding for the public health service is paramount. Within that, we believe that reducing barriers to research and training in behavioral science is warranted by the central role of behavior in many of our most pressing health problems and by the enormous potential of psychological science and other behavioral disciplines to reduce the suffering experienced by the millions of people who are suffering with behavior-based conditions. APS shares your commitment to addressing the health needs of the Nation and appreciates the opportunity to provide this testimony.

[This statement was submitted by Sarah Brookhart, Executive Director, Association for Psychological Science.]

PREPARED STATEMENT OF THE ASSOCIATION FOR RESEARCH IN VISION AND OPHTHALMOLOGY

EXECUTIVE SUMMARY

The Association for Research in Vision and Ophthalmology (ARVO), on behalf of its nearly 12,000 members—half in the U.S.—thanks Congress, particularly the House and Senate Appropriations Subcommittees on Labor, Health and Human Services, and Education (LHHS), for strong bipartisan support for the National Institutes of Health (NIH) funding increases from fiscal year 2016 through fiscal year 2019. ARVO appreciates the $9 billion increase that has helped the agency regain ground lost after years of effectively flat budgets. For fiscal year 2020, ARVO urges Congress to appropriate at least $41.6 billion to the NIH, a $2.5 billion or 6.4 percent increase over the fiscal year 2019 funding level. This increase would allow for meaningful growth above inflation in the base budget to support promising science across all Institutes and Centers (I/Cs). Funding at this level would also ensure that dollars from the Innovation Account, established through the 21st Century Cures Act, would supplement NIH's base budget, as intended, through dedicated funding for specific programs.

For fiscal year 2020, ARVO also encourages Congress to appropriate at least $850 million for the National Eye Institute (NEI), which is a $53 million or 6.4 percent increase over enacted fiscal year 2019. ARVO is concerned that the NIH and NEI budgets have not kept pace with biomedical inflation. For example, despite the total fiscal year 2016–2019 funding increases of $120 million, NEI's fiscal year 2019 enacted budget of $797 million is just 14 percent greater than the pre-sequester fiscal year 2012 budget of $702 million. When this amount is averaged over the past seven fiscal years, the 2 percent annual growth rate is less than the average annual biomedical inflation rate of 2.8 percent, thereby eroding the purchasing power and impact of these funds.

The NEI, which celebrated its 50th anniversary in 2018, is the world leader in sight-saving and vision-restoring research. We encourage Congress to ensure robust NEI funding that can help address the challenges of The Decade of Vision 2010–2020—as recognized by Congress in S. Res. 209 in 2009—which includes an aging population, disproportionate risk/incidence of eye disease in fast-growing minority populations, and the visual impact of numerous chronic diseases and their therapies.

Vision loss is costly to Americans. Investing in vision research to improve eye health can help to reduce healthcare costs and increase quality of life. The NEI's breakthrough research is a cost-effective investment that leads to treatments and therapies that delay, save and prevent healthcare expenditures. The NEI has been a leader in genetics/genomics research and regenerative medicine. For example:

Genetics/Genomics:

—NEI's Glaucoma Genetics Collaboration Heritable Overall Operational Database (NEIGHBORHOOD) Consortium has identified 133 genetic traits that predict with 75 percent accuracy a person's risk for developing glaucoma related to elevated intraocular pressure (IOP). Among the 133 traits, 68 had not been previously linked to IOP or the relate cellular processes, such as lipid metabolism and mitochondrial function, that contribute to IOP. By understanding these cellular processes that can increase IOP and cause optic nerve damage, clinicians may be able to make an earlier diagnosis and researchers may be able to develop therapies to potentially halt disease progression.

—NEI-funded research has also led to the discovery of genetic defects underlying dozens of rare eye disease, including the discovery of RPE65. When mutated, this gene causes an inherited form of blindness called Leber congenital amaurosis (LCA). In 2017, based on NEI's initial efforts, the Food and Drug Administration (FDA) approved a gene therapy that cures this condition. These gene-based discoveries are forming the basis for new therapies that treat or prevent disease deemed untreatable until now.

Regenerative Medicine:

—In 2013, NEI launched its Audacious Goals Initiative (AGI) focused on regenerative medicine with the goal of restoring vision in blind patients that had lost portions of their retina. After initially asking a broad constituency of scientists within the vision research community to consider what could be done if researchers employed this new era of biology, the AGI currently funds major research consortia that are developing innovative ways to visualize the retina system. Researchers can now look at individual nerve cells in the eyes of patients in an examination room and directly observe whether new treatments are successful. Another consortium is identifying biological factors that allow damaged nerve cells of the retina to regenerate. The AGI is gathering considerable momentum with current proposals to develop disease models that may accelerate clinical trials for therapies within the next decade.

—NEI plans a first-in-human clinical trial that would test a stem cell-based therapy using a patient's own cells, so called induced pluripotent stem cells (iPSC), to treat the "dry" form of Age-related Macular Degeneration (AMD), the leading cause of vision loss among people age 65 and older. In this trial, a patient's own blood-making cells, called CD34+ cells, are converted to iPSCs and then programmed to become retinal pigment epithelial (RPE) cells. The RPE cells nurture the photoreceptors cells, which are necessary for vision and which die in AMD. The therapy replaces RPE cells, which have died due to AMD, with new, fully functioning, iPSC-derived RPE, thereby rescuing remaining photoreceptor cells and ultimately vision.

THE NATION'S INVESTMENT IN THE NEI RESULTS IN NEW THERAPIES TO TREAT MAJOR EYE DISEASES

Since President Lyndon Johnson signed legislation creating the NEI in 1968, the Federal commitment has resulted in treatments and therapies for devastating diseases that cause vision loss. For example:

—*AMD:* The treatment of the "wet" form of AMD has made great strides resulting from use of Anti-Vascular Endothelial Growth Factor (VEGF) therapies. Last year, the NEI launched the AMD Ryan Initiative Study (ARIS), a prospective international study of patients that uses the latest advances in retinal imaging to identify biomarkers of the disease and targets for early therapeutic interventions.

—*Diabetic Retinopathy:* In the 1960s, about half of patients with diabetic retinopathy were blind within 5 years of diagnosis. NEI-sponsored clinical trials—starting in the early 1970s with the Diabetic Retinopathy Study and most recently with the Diabetic Retinopathy Clinical Research Network—have reduced the incidence of severe vision loss from diabetic retinopathy by 90 percent.

—*Glaucoma:* Eye pressure (IOP) appears to be the primary determining factor in the development of glaucoma for many patients. NEI research into primary open-angle glaucoma (POAG), the most common form of the disease, has resulted in two FDA-approved drug therapies in addition to those that have already emerged from NEI research. Targeting the eye's trabecular meshwork, which is a part of the eye responsible for reducing eye pressure by regulating fluid outflow from within the eye, the new generation of therapies reflects an expanding menu of drugs, potentially in combination with therapy, that lower IOP and better meet the needs of patients who do not respond to existing drugs or for whom older therapies have lost efficacy.

—*Optical Coherence Tomography (OCT):* Critical to the diagnosis and monitoring of treatments for the aforementioned eye diseases is an imaging technology called Optical Coherence Tomography (OCT). This non-invasive, high-resolution imaging technology displays a three-dimensional cross-sectional view of the layers of the retina. Developed over 25 years with $423 million in NIH and National Science Foundation (NSF) funding, OCT enables more personalized eye care and more efficient use of healthcare dollars. A December 2017 American Journal of Ophthalmology article reported that OCT saved Medicare $9 billion and patients $2.2 billion in co-pays by reducing unnecessary injections. As the technology continues to be applied to new medical conditions, such as Alzheimer's disease and Parkinson's disease, it supports a private commercial market of $1 billion and more than 16,000 high-paying jobs. These numbers suggest that in just this single area of research, the U.S. Government saw a 2,100 percent return on investment. https://www.ajo.com/article/S0002-9394(17)30419-1/fulltext

The next breakthroughs in technologies or treatments to save sight may be around the corner. Increased funding for the NIH and NEI in fiscal year 2020 may expedite the discovery of these technologies and treatments that will impact the lives of those facing vision loss and their families.

NEI's fiscal year 2019 enacted budget of $797 million is just 0.55 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. Of the $717 billion annual cost of vison 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 $2.40 per person, per year for vision research, while the cost of treating low vision and blindness is at least $6,680 per person, per year. https://www.preventblindness.org/cost-vision-problems

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, ARVO's educational foundation) reported that most 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. http://jamanetwork.com/journals/jamaophthalmology/article-abstract/2540516?resultClick=1

NEI funding is also crucial to young scientists' research. Flat funding and cuts to NIH funding will impact their ability to move their careers and research forward. Recognizing the potential of young scientists, ARVO has focused efforts in recent years to support the next generation of scientists through travel grants to our annual meeting and awards to support research. Additionally, ARVO has created a Science Communication Training Fellowship to teach young scientists how to communicate about their science research to various audiences. It is crucial that these young scientists continue receiving support for their research through NEI grants and funding if they are to prevail as the next generation of leaders in vision research.

Please remember that investing in vision health is an investment in overall health. NEI's breakthrough research leads to treatments and therapies that may delay, save, and prevent healthcare expenditures. It can also increase productivity and improve the quality of life, as vision loss is associated with increased depression and accelerated mortality.

To support this important work, on behalf of the eye and vision research community, ARVO asks Congress to maintain the momentum of research that is vital to vision health, as well as overall health and quality of life and requests fiscal year 2020 NIH funding of at least $41.6 billion and NEI funding of $850 million.

ABOUT ARVO

ARVO's mission is to advance research worldwide into understanding the visual system and into preventing, treating and curing its disorders. Our members include nearly 12,000 researchers—with about half in the U.S.—representing more 80 countries. This is done through meetings, education, partnerships, fellowships and programs that drive collaboration, innovation and the advancement of eye and vision science with a goal of saving sight. Learn more at www.ARVO.org

[This statement was submitted by Iris M. Rush, CAE, Executive Director, Association for Research in Vision and Ophthalmology.]

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 154 accredited U.S. and 17 accredited Canadian medical schools; nearly 400 major teaching hospitals and health systems, including 51 Department of Veterans Affairs medical centers; and more than 80 academic societies. Through these institutions and organizations, the AAMC serves the leaders of America's medical schools and teaching hospitals and their 173,000 full-time faculty members, 89,000 medical students, 129,000 resident physicians, and more than 60,000 graduate students and postdoctoral researchers in the biomedical sciences.

In fiscal year 2020, the AAMC requests the following for Federal priorities essential in assisting medical schools and teaching hospitals to fulfill their missions of education, research, and patient care: at least $41.6 billion for the National Institutes of Health (NIH), including funds provided through the 21st Century Cures Act for targeted initiatives; $460 million in budget authority for the Agency for Healthcare Research and Quality (AHRQ); $690 million for the Title VII health professions and Title VIII nursing workforce development programs, and $400 million for the Children's Hospitals Graduate Medical Education (CHGME) program, at the Health Resources and Services Administration (HRSA)'s Bureau of Health Workforce; and continued support for student aid through the Department of Education. The AAMC appreciates the Subcommittee's longstanding, bipartisan efforts to strengthen these programs.

We recognize that the impractical fiscal year 2020 budget caps imposed by the Budget Control Act of 2011 hold the potential to undermine necessary investment in the full range of critical Federal priorities. The AAMC is among the hundreds of organizations urging a bipartisan budget deal to increase the caps for nondefense discretionary spending and advocating a significant increase in the Subcommittee's 302(b) allocation in fiscal year 2020. We urge Congress to take these steps to enable full investment in the priorities outlined below.

National Institutes of Health. Congress's longstanding bipartisan support for medical research has contributed greatly to improving the health and well-being of all

Americans. The foundation of scientific knowledge built through NIH-funded research drives medical innovation that improves health through new and better diagnostics, improved prevention strategies, and more effective treatments. Over half of the life-saving research supported by the NIH takes place at 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 $39.1 billion in the fiscal year 2019 omnibus spending bill for medical research conducted and supported by the NIH, which builds off meaningful increases for NIH since fiscal year 2016. Additionally, the AAMC thanks the Subcommittee for recognizing the importance of continuing Federal support for facilities and administrative expenses and retaining the salary cap at Executive Level II of the Federal pay scale. The AAMC is concerned that proposals to undermine salary support would, as described in NIH's fiscal year 2020 congressional justification, "limit the number of applicants with sufficient resources to participate in federally-funded research," and ultimately weaken research nationwide. This consequence would directly counter the Subcommittee's efforts over the years to strengthen the Nation's research enterprise.

In fiscal year 2020, the AAMC supports the Ad Hoc Group for Medical Research recommendation that Congress provide at least $41.6 billion for NIH, including funds provided through the 21st Century Cures Act for targeted initiatives. This funding level would continue the momentum of recent years by enabling meaningful base budget growth over biomedical inflation to help ensure stability in the Nation's research capacity over the long term. Securing a reliable, robust budget trajectory for NIH is key in positioning the agency—and the patients who rely on it—to capitalize on the full range of research in the biomedical, behavioral, social, and population-based sciences.

Scientific discoveries rely on support from Congress. We must continue the current trajectory if we are to strengthen our Nation's research capacity and solidify our global leadership in medical research, ensure a biomedical research workforce that reflects the racial and gender diversity of our citizenry, and inspire a passion for science in current and future generations of researchers.

Agency for Healthcare Research and Quality. Complementing the medical research supported by NIH, AHRQ sponsors health services research designed to improve the quality of healthcare, decrease healthcare costs, and provide access to essential healthcare services by translating research into measurable improvements in the healthcare system. As the only Federal agency with the sole purpose of generating evidence to make healthcare safer; higher quality; and more accessible, equitable, and affordable, AHRQ also works to ensure such evidence is available across the continuum of healthcare stakeholders, from patients to payers to providers. The AAMC joins the Friends of AHRQ in recommending $460 million in budget authority for AHRQ in fiscal year 2020.

Health Professions Funding. HRSA's Title VII health professions and Title VIII nursing workforce development programs allow grantees to test educational innovations, respond to changing delivery systems and models of care, and address timely topics in their communities. By assessing community needs and emphasizing interprofessional education and training, Title VII and VIII programs bring together cross-disciplinary knowledge and skills to provide effective, efficient and coordinated care. Through loans and scholarships to students, and grants and contracts to academic institutions and non-profits, these programs fill the gaps in the supply of health professionals not met by traditional market forces. The full spectrum of Title VII programs, from workforce diversity programs to geriatric programs is essential to prepare medical professionals to adapt to the changing needs of the Nation's aging and diverse population. Studies demonstrate that the programs graduate more minority and disadvantaged students and prepare providers that are more likely to serve in Community Health Centers and the NHSC. The programs also support faculty development, curriculum development, and continuing education opportunities. These are all important components to ensure faculty and providers are equipped to meet the Nation's changing needs and train the next generation of health professionals. The AAMC joins the Health Professions and Nursing Education Coalition (HPNEC) in recommending $690 million for these important workforce programs in fiscal year 2020.

The AAMC is grateful for the House of Representatives providing $680 million for Title VII and Title VIII programs, and an additional $55 million for the new Loan Repayment Program for Substance Use Disorder Treatment Work, the Mental and substance Use Disorder Workforce Training Demonstration, and Nurse Practitioner Optional Fellowship Program. These programs are essential to ensuring we have a trained health workforce to treat patients who are affected by substance use disorder. While we support the inclusion of these programs into Titles VII and VIII, it is imperative that they are an expansion of Titles VII and VIII and are not funded at the expense of current programs.

In addition to funding for Title VII and Title VIII, HRSA's Bureau of Health Workforce also supports the Medical Student Education (MSE), Teaching Health Center Graduate Medical Education (THCGME), and Children's Hospitals Graduate Medical Education (CHGME) programs. We are grateful for the $40 million provided by the House of Representatives for MSE grants, which incentives medical students to enter primary care in rural and medically underserved communities. Additionally, we appreciate the mandatory appropriations provided under the Bipartisan Budget Act of 2018 for THCs in fiscal year 2018 and fiscal year 2019 to support new and expanded primary medical residency programs in community-based ambulatory patient care settings. Further, we urge Congress to fund THCs in fiscal year 2020 and beyond without cutting mandatory or discretionary support for other Federal physician training programs. The CHGME program provides critical Federal graduate medical education support for children's hospitals to prepare the future primary care and specialty care workforce for our Nation's children. We support $400 million for the CHGME program in fiscal year 2020.

The AAMC appreciates the funding provided under the Bipartisan Budget Act of 2018 for NHSC, and supports $475 million in total funding for the program in fiscal year 2020. This $60 million (15 percent) increase is the first stage of a 5-year systematic doubling of the NHSC to meet the needs of underserved communities. 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 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.

Additional Programs. The AAMC supports at least $474 million for the Hospital Preparedness Program, in addition to $40 million to continue the regional preparedness program created to address Ebola and other special pathogens, including funding for regional treatment centers, frontline providers, and the National Ebola Training and Education Center (NETEC), expiring in fiscal year 2019. The AAMC appreciates that the president's fiscal year 2020 budget proposal requests $4 million to support grants to medical schools and teaching hospitals to develop curricular resources on medication-assisted treatment. The AAMC supports the programs authorized under Sections 3202 and 7101 of the SUPPORT Act (Public Law 115–271) to enhance medical education, and we encourage their full funding.

The AAMC urges the Subcommittee to sustain student loan and forgiveness programs for graduate and professional students at the Department of Education, including GradPLUS loans and Public Service Loan Forgiveness (PSLF). The average graduating debt of medical students is currently $200,000, and total repayment can range from $365,000 to $440,000.

Once again, the AAMC appreciates the opportunity to submit this statement for the record and looks forward to working with the Subcommittee as it prepares its fiscal year 2020 spending bill.

PREPARED STATEMENT OF THE ASSOCIATION OF FARMWORKER OPPORTUNITY PROGRAMS

Chairman Blunt and Ranking Minority Member Murray:

Thank you for the opportunity to present to you and your subcommittee the testimony of the Association of Farmworker Opportunity Programs (AFOP) in support of the Nation's more than 50-year commitment to providing eligible agricultural workers the opportunity to achieve the American Dream for themselves and their families. As you begin work on your fiscal year 2020 Labor-Health and Human Services-Education appropriations bill, AFOP encourages you to build on the foundations laid by the highly successful programs described below by fully funding them in the coming fiscal year: National Farmworker Jobs Program (NFJP), United States Department of Labor (DOL) Employment and Training Administration ($96,211,000); and Susan Harwood Training Grants, DOL Occupational Safety and Health Administration ($10,537,000). Not only do these programs maximize the Federal Government's investment in them, they also generate for employers the qualified and healthy workers essential to their growth. These programs also dramatically change peoples' lives for the better, often in rural areas, allowing them to enjoy economic success and participate more fully in our great Nation. Thank you for supporting these very effective programs and the excellent results they bring for society's most vulnerable.

NATIONAL FARMWORKER JOBS PROGRAM

NFJP is the bedrock of the Nation's commitment to helping agricultural workers upgrade their skills in and outside agriculture, providing employers with what they increasingly say they need: hardworking, committed, well-trained, skilled workers. Administered by DOL, NFJP provides funding through a competitive grant process to 52 community-based organizations and public agencies nationwide that assist workers and their families to attain greater economic stability. One of DOL's most successful employment training programs, NFJP helps agricultural workers acquire the new skills they need to start careers that offer higher wages and a more stable employment outlook. In addition to employment and training services, the program provides supportive services that help agricultural workers retain and stabilize their current agriculture jobs, as well as enable them to participate in up-training and enter new careers. NFJP housing assistance helps meet a critical need for the availability and quality of agricultural worker housing, and supports better economic outcomes for workers and their families. NFJP also facilitates the coordination of services through the American Job Center network for agricultural workers so they may access other services of the public workforce system.

The agricultural workers who come to NFJP seek the training to secure and excel in the in-demand jobs employers say they find challenging to fill. In doing so, the workers establish the financial foundation that allows them and their families to escape the chronic unemployment and underemployment they face each year. Many NFJP participants enter construction, welding, healthcare, and commercial truck-driving. Others train for the solar/wind energy sector, culinary arts, and for positions such as machinists, electrical linemen, and a variety of careers in and outside of agriculture. To be eligible for NFJP, workers must be low-income, depend primarily on agricultural employment, and provide proof of American citizenship or work authorization. Additionally, male applicants must have registered with the Selective Service.

Agricultural workers are some of the hardest working individuals in this country, enduring tremendous physical and financial hardships in providing produce Americans eat every day. Yet, agricultural workers remain among the Nation's most vulnerable employees and job seekers, facing significant barriers to work advancement, including:

—The average agricultural worker family of four earns just $20,000 per year, well below the national poverty line.
—English-language fluency is a substantial challenge for many.
—More than half the children of migratory agricultural workers drop out of school, and, among all agricultural workers, the median highest grade completed is 9th grade (National Agricultural Workers Survey).
—Due to poverty and their rural locations, most agricultural workers have extremely limited access to transportation.

Despite these barriers, NFJP continues to be one of the most successful Federal job training programs, exceeding all of DOL's goals. In 2015 alone, NFJP service organizations provided more than 16,000 agricultural workers with services, according to DOL. Extrapolating, these NFJP providers have served more than 160,000 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 Harwood grant program, through which AFOP has augmented pesticide safety training with curricula to help workers recognize and avoid the dangers of heat stress so common in the fields. In supporting this funding, you can arm the Nation's agricultural workers with the knowledge they need to keep themselves safe on the job. The NFJP network of some 268 trainers in 28 States trains agricultural workers on how to protect against pesticide poisoning and heat stress. Trainers then follow up with agricultural workers to assess knowledge gained and retained, and changes in labor practice. Since 1995, more than 445,000 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 this instruction, the network's trainers offer access to other services and create a ripple effect of positive impact, improving the quality of life for agricultural workers and their families, which is what NFJP organizations do best.

Thank you for supporting these worthy programs. AFOP stands ready to assist you in any way as you proceed with your very important work.

[This statement was submitted by Daniel J. Sheehan, Executive Director, Association of Farmworker Opportunity Programs.]

PREPARED STATEMENT OF THE ASSOCIATION OF INDEPENDENT RESEARCH INSTITUTES

The Association of Independent Research Institutes (AIRI) thanks the Subcommittee for its long-standing and bipartisan leadership in support of the National Institutes of Health (NIH). We continue to believe that science and innovation are essential if we are to improve our Nation's health, sustain our leadership in medical research, and remain competitive in today's global information and innovation-based economy. AIRI urges the Subcommittee to provide NIH with at least $41.6 billion in fiscal year 2020. AIRI also urges the Subcommittee to reject the harmful salary support and salary cap policies proposed in the President's fiscal year 2020 budget request, as any changes to salary policy would disproportionately impact independent research institutes.

First, we would like to deeply thank the Subcommittee for providing another increase of $2 billion for NIH in fiscal year 2019 and securing funding before the start of the fiscal year. The Subcommittee's support of NIH is strongly demonstrated by these much-needed funds for life-saving biomedical research. However, there is still much more to do. NIH is tackling vast, interdisciplinary problems such as the opioid crisis, the development of a universal flu vaccine, and Alzheimer's disease; therefore, continued budget certainty is needed for the agency to predictably fund new and ongoing grants and consider emerging initiatives necessary to improving human health. To ensure cutting-edge research at independent research institutes is not disrupted, AIRI strongly supports a topline of $41.6 billion for NIH in fiscal year 2020.

AIRI is a national organization of more than 90 independent, non-profit research institutes that perform basic and clinical research in the biological and behavioral sciences. AIRI institutes vary in size, with budgets ranging from a few million to hundreds of millions of dollars. In addition, each AIRI member institution is governed by its own independent Board of Directors, which allows our members to focus on discovery-based research while remaining structurally nimble and capable of adjusting their research programs to emerging areas of inquiry. Investigators at independent research institutes consistently exceed the success rates of the overall NIH grantee pool, and they receive about 10 percent of NIH's peer-reviewed, competitively-awarded extramural grants.

The partnership between NIH and America's scientists, research institutions, universities, and medical schools is unique and highly-productive, leveraging the full strength of our Nation's research enterprise to foster discovery, improve our understanding of the underlying cause of disease, and develop the next generation of medical advancements that deliver more treatments and cures to patients.

Not only is NIH research essential to advancing health, it also plays a key economic role in communities nationwide. In fiscal year 2018, NIH invested $28.05 billion, or almost 75 percent of its budget, in the biomedical research community. This investment supported more than 430,000 jobs nationwide and generated nearly $74 billion in economic activity across the U.S.[1] AIRI member institutes are particularly relevant in this regard, as they are located across the country, including in many smaller or less-populated States that do not have major academic research institutions. In many of these regions, independent research institutes are major employ-

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[1] NIH's funding information and economic impact data comes from United for Medical Research's 2019 State-By-State Update, http://www.unitedformedicalresearch.com/wp-content/uploads/2019/03/NIHs-Role-in-Sustaining-the-US-Economy-2019-Update-FINAL.pdf.

ers and local economic engines, and they exemplify the positive impact of investing in research and science.

The NIH model for conducting biomedical research, which involves supporting scientists at universities, medical centers, and independent research institutes, provides an effective approach to making fundamental discoveries in the laboratory that can be translated into medical advances that save lives. AIRI member institutions are private, stand-alone research centers that set their sights on the vast frontiers of medical science. However, AIRI member institutes are especially vulnerable to reductions in the NIH budget, as they do not have other reliable sources of revenue to make up the shortfall.

AIRI opposes the harmful salary proposal in the President's fiscal year 2020 budget that would reduce the salary cap to Executive Level V from Executive Level II for extramural researchers and the proposal to limit the total amount of investigator salary payable on a grant. These policies would disproportionately affect early-career investigators and independent research institutes and hinder AIRI members' ability to recruit and retain talented researchers. The caps also negatively affect the confidence of future researchers in the viability of a career in biomedical sciences, severely harming the competitiveness and capacity of the U.S. biomedical enterprise.

The Federal Government has an irreplaceable role in supporting investigators and medical research. No other public, corporate, or charitable entity is willing or able to provide the broad and sustained funding for the cutting-edge research necessary to yield new innovations and technologies of the future. NIH supports long-term competitiveness for American workers, forming one of the key foundations for U.S. industries like biotechnology, medical devices, and pharmaceutical development, among others. Unfortunately, any erosion to the national commitment to medical research could threaten our ability to support a medical research enterprise that takes full advantage of existing and emerging scientific opportunities.

AIRI member institutes' flexibility and research-only missions provide an environment particularly conducive to creativity and innovation. Independent research institutes possess a unique versatility and culture that encourages them to share expertise, information, and equipment across research institutions, as well as neighboring universities. These collaborative activities help minimize bureaucracy and increase efficiency, allowing for fruitful partnerships in a variety of disciplines and industries. Also, unlike institutes of higher education, AIRI member institutes focus primarily on scientific inquiry and discovery, allowing them to respond quickly to the research needs of the Nation.

AIRI deeply thanks the Subcommittee for its important work dedicated to ensuring the health of the Nation, and we appreciate this opportunity to urge the Subcommittee to continue the success of NIH by providing $41.6 billion in fiscal year 2020 and reaffirm support for NIH's current salary policies to strengthen our Nation's investment in life-saving medical research.

PREPARED STATEMENT OF THE ASSOCIATION OF MINORITY HEALTH PROFESSIONS SCHOOLS

SUMMARY OF FISCAL YEAR 2020 RECOMMENDATIONS

Health Resources and Services Administration

- —$424 million for Title VII Health Professions Training Programs
  - —$45.21 million for HRSA's Minority Centers of Excellence (COE) Program
  - —$47.95 million for HRSA's Health Careers Opportunity Program (HCOP)
  - —$1.75 million for HRSA's Faculty Loan Repayment
  - —$63.39 million for HRSA's Scholarships for Disadvantaged Students
  - —$67 million for HRSA's Area Health Education Center (AHEC) Program

National Institutes of Health

- —$41.6 billion for the National Institutes of Health
  - —$336 million for the National Institute on Minority Health and Health Disparities (NIMHD)
    - —Improve NIMHD's administration of the Research Centers at Minority Institution (RCMI) program to refocus it on supporting minority institutions
    - —Improve NIMHD's administration of the Research Endowment Program to reverse the arbitrary limits placed on participating institutions

Centers for Disease Control & Prevention

—$60 million for CDC's Racial & Ethnic Approaches to Community Health (REACH) Program

Office of the HHS Secretary

—$60 million for the HHS Office of Minority Health

Department of Education

—$125 million for the Historically Black Graduate Institution (HBGI) Program

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Chairman Blunt, Ranking Member Murray, and distinguished members of the subcommittee, thank you for the opportunity to present testimony and thank you for your leadership in addressing challenges facing the health workforce, health disparities, and medically underserved communities. I am Dr. Valerie Montgomery Rice, President & Dean of the Morehouse School of Medicine. Our school was one of the founding members of the Association of Minority Health Professions Schools (AMHPS), established in 1976 to promote a national minority health agenda by addressing the needs of the health workforce and improving health status in medically-underserved communities. Historically, the just twelve (12) schools of our association have trained half of the Black physicians in the US, half of the Black dentists, 75 percent of the Nation's Black pharmacists, and 70 percent of the Nation's Black veterinarians. Our graduates disproportionately serve in medically underserved communities, in primary care specialties. In fact, Morehouse School of Medicine, and Meharry Medical College (our sister HBCU medical school in Nashville) were named #1 and #2 in social mission compared to all US medical schools by the Annals of Internal Medicine. Our institutions are committed to resolving the healthcare needs of every American and are at the forefront of this important effort. Your investment in our institutions is paying off.

AMHPS membership includes the health professions institutions of Morehouse School of Medicine, Howard University, Meharry Medical College, Charles Drew University, Florida A&M University, Hampton University, Texas Southern University, Xavier University, and Tuskegee University. Today, AMHPS institutions compete for key programs administered by HRSA, CDC, NIH, the HHS Office of Minority Health, and the Department of Education to advance our collective mission, as well as the mission of this subcommittee: to diversify the health workforce, advance research that addresses health equity, and improve health outcomes.

HRSA's Title VII health professions training and pipeline programs are key resources for addressing the Nation's workforce shortages and health challenges. HRSA's Minority Centers of Excellence (COE) address this challenge through its focus on improving student recruitment and performance, strengthening curricula in cultural competence, and training students to provide health services to minority individuals. The Health Careers Opportunity Program (HCOP) provides a mechanism for us to mitigate theses shortages by providing grants to health professions institutions in order to support pipeline, preparatory, and recruiting activities in the health professions. These grants are utilized to encourage minority and economically disadvantaged students to pursue careers in the health professions at the collegiate and high school levels. Students who demonstrate that they have the talent and potential to become a health professional can access the Scholarships for Disadvantaged Students program. HRSA programs are essential for pipeline recruitment activities and through the HCOPs, COEs, or AHECs, these programs are highly meaningful for recruiting, mentoring, and training students from underrepresented minority, rural, and disadvantaged backgrounds.

The National Institute on Minority Health & Health Disparities (NIMHD) has been a key partner of the AMHPS institutions. The NIMHD has invested in improving our research capabilities through the ongoing development of our faculty, labs, and other learning resources. These investments take form through the NIMHD's extramural programs such as the Research Centers at Minority Institutions program, the Research Endowment Program and its Centers of Excellence Program. NIMHD also supports biomedical research focused on eliminating health disparities through various funding opportunities and develops a comprehensive plan for research on minority health at the NIH.

Madam Chair, we have contended with some challenges recently in the administration of several NIMHD programs. With the retirement of the longstanding director of the NIMHD, a temporary acting director, and now a new permanent director, NIMHD's keystone programs such as RCMI and Research Endowments that are critical to our infrastructure are no longer prioritized by the institute. The Research Centers at Minority Institutions (RCMI) program was initiated by this very subcommittee in 1986 and championed by the Honorable Louis Stokes (D–OH). The one program at NIH designated to support research infrastructure specifically at minority health professions schools (hence the name of the program) is no longer limited to minority institutions, even though the language establishing RCMI specifically states "an institution must have more than 50 percent minority enrollment..."

Arbitrary administrative changes in the Research Endowment Program—established to help institutions like Morehouse School of Medicine, which have modest endowments—have left the very institutions the program was intended to help, unable to compete for the program. This is in light of the fact that no school has reached the endowment level stated as the goal of the program. Neither RCMI nor the Research Endowment program is given much discussion by the NIMHD congressional budget justification. We need help from this subcommittee to reverse these poor decisions made by NIMHD.

Racial and Ethnic Approaches to Community Health (REACH) is a national program administered by the Centers for Disease Control and Prevention (CDC) to reduce racial and ethnic health disparities. Through REACH, recipients plan and carry out local, culturally appropriate programs to address a wide range of health issues among African Americans, and other minority groups. REACH provides funds to State and local health departments, Tribes, universities, and community-based organizations. Recipients use these funds to build strong partnerships to guide and support the program's work.

The Department of Education's Strengthening Historically Black Graduate Institutions (HBGI) program (Title III, Part B, Section 326) is extremely important to AMHPS. The HBGI program is a successful program that provides crucial financial support for HBGIs that are producing underrepresented graduates at the highest levels of academia, including physicians and graduates in the Science, Technology, Engineering, Arts, and Math ("STEAM") disciplines. AMHPS supports continuing the existing "hold harmless" provision contained in the HBGI program statute as well. The "hold harmless" provision requires that currently participating institutions receive funding support at a level no less than the previous year as long as they are providing sufficient matching funds, meeting program objectives, and the annual appropriated amount is adequate to support it. This provision provides participating schools a level of budget stability and certainty, notwithstanding the addition of new institutions.

Chairman Blunt and Ranking Member Murray, please allow me to express my appreciation to you and the members of this subcommittee for your efforts to revitalize our Nation's commitment to the health workforce and health equity. As you begin the fiscal year 2020 process, we look forward to working with the subcommittee to continue prioritizing initiatives that improve the quality of health and patient care, research in health disparities, and health professionals going into the health workforce.

[This statement was submitted by Valerie Montgomery Rice, MD, FACOG, President & Dean, Morehouse School of Medicine.]

PREPARED STATEMENT OF THE ASSOCIATION OF SCIENCE-TECHNOLOGY CENTERS, THE AMERICAN ALLIANCE OF MUSEUMS, THE ASSOCIATION OF CHILDREN'S MUSEUMS, AND THE ASSOCIATION OF SCIENCE MUSEUM DIRECTORS

Chairman Blunt, Ranking Member Murray, and Members of the Subcommittee:

Thank you for accepting this statement submitted by the Association of Science-Technology Centers (ASTC), the American Alliance of Museums (AAM), the Association of Children's Museums (ACM), and the Association of Science Museum Directors (ASMD). We are Cristin Dorgelo, President and CEO of ASTC; Laura L. Lott, President and CEO of AAM; Laura Huerta Migus, Executive Director of ACM; and Bonnie Styles, Executive Director of ASMD.

We appreciate the opportunity to present the views of our associations to the Subcommittee for its consideration as it prepares to write the fiscal year 2020 Labor, Health and Human Services, Education, and Related Agencies Appropriations bill, particularly regarding the Science Education Partnership Awards (SEPA) at the National Institutes of Health, the Office of Museum Services (OMS) within the Institute of Museum and Library Services (IMLS), and the U.S. Department of Education's 21st Century Learning Centers and Title II Effective Teaching Program.

Our associations represent more than 5,000 member organizations in every State and district in America, including science centers and museums, nature centers, aquariums, zoos, planetariums, botanical gardens, and natural history and children's museums, as well as companies, consultants, and other organizations that share an interest in science education and public engagement in science.

Taken together, our national reach is a vital resource for fostering rich public engagement in the importance of science and many other subjects and disciplines towards building a bright future and opportunity for all.

Our place-based organizations are leading institutions in the efforts to promote education in science, technology, engineering, and mathematics (STEM), developing rich, innovative, and effective science-learning experiences. We are helping to create the future STEM workforce and inspiring people of all ages about the wonders and the meaning of science in their lives. And our members are trusted and valued by their communities—a recent national public opinion poll, showed that 95 percent of voters would approve of lawmakers who acted to support museums and 96 percent of voters want Federal funding for museums to be maintained or increased (Museums and Public Opinion, Wilkening, S. and AAM, 2018).

In the past, we have testified on behalf of the specific funding levels for programs under this Subcommittee's jurisdiction. But today we also want to commend this Subcommittee through a look at the bigger picture—the overall science budget of the U.S. Federal Government.

As you are well aware, for the past 2 years the Administration proposed significant cuts to the budgets of a number of domestic agencies. Included in the list of impacted programs were a number of science agencies and science programs. Similar cuts have been proposed in the Administration's fiscal year 2020 budget.

We want to thank you for not allowing the cuts to move forward. We urge you to reject them in the fiscal year 2020 budget as well. Of course, the first hurdle to cross to fully fund all the programs is to raise or repeal the budget caps. To do otherwise will result in devastating impacts to America's scientific enterprise and force you to forego critical investments in our students at a time when we must equip all Americans with the skills they need to thrive in the future workforce.

Taken together, the investments being made by the U.S. Federal Government in science and research is larger than ever. On behalf of the all the members of ASTC, AAM, ACM, and ASMD—and the communities they serve—we want to say thank you, with gratitude for a job well done.

Our associations and the member organizations we represent in America's communities were active and vocal supporters of a robust budget for science and for STEM education budgets last year. Many of our institutions hosted science days, participated in community celebrations of science, and reached out to their elected representatives to make the case for the importance of science and STEM education. This year and into the future, our associations will all continue to advocate for robust research, STEM education, and science-engagement funding at every opportunity.

In December 2018, a new 5-year Federal STEM Education Strategic Plan was published by the interagency National Science and Technology Council's Committee on STEM Education. The new plan reflects a vital roadmap for public-private cooperation to advance STEM education, and we encourage the Subcommittee to fund programs that support our museum members in making further progress towards the plan's aspirational goals, which include:

—Building strong foundations for STEM literacy by ensuring that every American has the opportunity to master basic STEM concepts, including computational thinking, and to become digitally literate.

—Increasing diversity, equity, and inclusion in STEM and providing all Americans with lifelong access to high-quality STEM education, especially those historically underserved and underrepresented in STEM fields and employment.

—Preparing the STEM workforce for the future by creating authentic learning experiences that encourage and prepare learners to pursue STEM careers.

School-aged youth spend 80 percent of their time outside of the classroom. Research has consistently shown that learning experiences outside of the formal classroom are vitally important to youth's future interest and capacity in STEM (National Research Council, 2006, 2009, 2015).

Every day, our science centers, museums, zoos, and aquariums open their doors for students and the public. Every day, throughout the United States, they reach out to students of underserved populations in both urban and rural areas, so that quality STEM education can be accessed by every American student. Every day, they welcome girls and youth from backgrounds historically underrepresented in STEM fields, providing positive examples and experiential learning opportunities so that these youth know there is a place for them in the scientific community.

Every day, our museums provide educational experiences with science, technology, and other subjects in interesting, innovative, and effective ways—including through transdisciplinary approaches that connect youth with how science, technology, engineering, and math relate to community issues and real-world problem solving. Every day, staff at our museums train teachers on effective science teaching practices and develop curriculum aligned with Next Generation Science Standards in partnership with local schools. Every day, they open their doors and reach out to every student in their communities, to ensure that our Nation has the trained STEM workforce we will need for the future.

With continued Congressional support for programs that support informal STEM education, afterschool, out-of-school, and summer learning, and public engagement in science programs, you will make our efforts more effective.

Turning to specifics, ASTC strongly urges the Subcommittee to appropriate at least $20.1 million for the Science Education Partnership Awards (SEPA) at the National Institutes of Health.

We also urge you to fully fund the Institute of Museum and Library Services (IMLS) at or above $257 million, and to provide at least $38.6 million for its Office of Museum Services. The museum programs at IMLS provide crucial resources for the informal science activities at science centers and museums throughout the country.

Finally, within the U.S. Department of Education, we urge you to provide at least $2.065 billion for the Title II Effective Teaching Program, at least $1.17 billion for the Title IV–A Students Support and Academic Enrichment program, and at least $1.32 billion for the Title IV–B 21st Century Learning Centers.

In short, we strongly urge you to again reject the Administration's proposals to cut these programs and to maintain funding levels in fiscal year 2020 in a new, bipartisan budget deal that raises the spending caps and supports American innovation through critical investments in science, advancing science education, and public engagement in science.

We continue to thank this Subcommittee for all its support of a robust science budget. You have demonstrated your support for crucial programs that promote STEM education for our Nation's students. Like our organizations, you recognize these are vital investments in our future, and we thank you in advance for taking action accordingly.

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 2020 appropriations for the U.S. Department of Health and Human Services (HHS). ASTHO is requesting $8.3 billion for the Centers for Disease Control and Prevention (CDC), $824 million for the Public Health Emergency Preparedness Program (PHEP), $170 million for the Preventive Health and Health Services Block Grant (Prevent Block Grant), and $50 million for the Infectious Disease Rapid Response Reserve Fund. Under the Assistant Secretary for Preparedness and Response (ASPR), we are requesting $474 million for the Hospital Preparedness Program (HPP) and $49.5 million to sustain the Regional Treatment Network for Ebola and Other Special Pathogens (RTNESP) and the National Ebola Training and Education Center (NETEC). Additionally, we are requesting $8.56 billion in discretionary funding for the Health Resources and Services Administration (HRSA) and a $500 million increase for the Substance Abuse and Mental Health Services Administration (SAMHSA) Substance Abuse Prevention and Treatment (SAPT) Block Grant.

ASTHO is the national nonprofit organization representing the public health agencies of the United States, the U.S. territories and freely associated States, and the District of Columbia. ASTHO members, the chief health officials of these jurisdictions, are dedicated to ensuring excellence in public health practice. The mission of our Nation's governmental health agencies is to protect and improve the health of the population, everywhere, every day. The work of public health is often invisible, and sometimes it is only in a crisis when the value and importance of sustained investment in public health becomes apparent. Those crises, unfortunately, happen all too often: the current measles and hepatitis A outbreaks, natural disasters, rising obesity rates, the long-term impact of Zika on the developing brains of young children, the opioid epidemic, and many others highlight the important work of disease prevention and health protection that is at the core of public health's mission.

Just like our transportation system, our healthcare system, and our air traffic control system, the governmental public health system needs a predictable, sustained, and increased investment to deliver the essential public health services all Americans expect and enjoy. However, I fear this will not be possible under current law. As you know all too well, sequestration returns this year with a $55 billion cut to non-defense discretionary spending as proposed by the President's Budget. Public health funding simply has not kept pace with the requirements for our mission.

Governmental public health systems are crumbling at every level due to ongoing underfunding and a growing population. ASTHO's "22x22" campaign, endorsed by over 80 national organizations, urges Congress to increase funding for the CDC by 22 percent by fiscal year 2022. We request $8.3 billion for CDC overall. This increase is important because American life expectancy has declined for the first time in decades due to heart disease, stroke, diabetes and drug overdoses. Federal investment in public health has not kept pace with inflation nor the considerable challenges posed by infectious disease outbreaks, extreme weather events, and other emergencies. According to a 2017 Trust for America's Health report, only 3 percent of all health spending is directed to public health out of the $3.36 trillion spent on healthcare. Finally, the waning public health workforce strains the ability of State and local public health departments to protect and promote the health of the population. The "22x22" campaign is an effort to bolster CDC's funding over the next 4 years to eventually reach $8.8 billion for the agency by fiscal year 2022. One of the most striking examples of the need for increased, predictable, and sustained funding for the CDC is the recent measles outbreak—an entirely preventable crisis. Vaccines are one of the core functions of the public health systems in our country. Addressing outbreaks requires a strong, coordinated response from Federal, State, territorial, and local governments. In these scenarios, the CDC—and the funding it provides to these entities—is critical. State and territorial health departments dispense vaccines and also provide outreach and education about their effectiveness, all while investigating pockets of infection in order to contain the spread of disease. Establishing and maintaining solid public health systems allow health departments to prevent, protect, respond, and recover from events and reduce the human and financial tolls.

Critical to public health preparedness and response is the support public health receives from the PHEP Cooperative Agreement, for which we request $824 million. Since its establishment in 2002, the program has invested in States and territories to create and maintain foundational capabilities. It is critical to provide stable and sufficient health emergency preparedness funding to maintain a standing set of core capabilities, so they are ready when needed. The program funding—once at $918 million in 2002—is 26 percent lower at $675 million, with public health threats not experiencing similar declines. In close partnership with the PHEP program is the Hospital Preparedness Program (HPP). ASTHO requests $474 million for HPP. As the only source of Federal funding that supports regional healthcare system preparedness, HPP promotes a sustained national focus to improve patient outcomes, minimizes the need for supplemental State and Federal resources during emergencies, and enables rapid recovery. The work of these programs is something that we should all be proud of and, therefore, continue to increase funding for both. In addition to the HPP, we are requesting that Congress provide $49.5 million to sustain the Regional Treatment Network for Ebola and Other Special Pathogens (RTNESP) and the National Ebola Training and Education Center (NETEC) that are under ASPR's leadership. Moreover, ASTHO is grateful for including $50 million for an Infectious Diseases Rapid Response Reserve Fund at the CDC in fiscal year 2019. This allows CDC to quickly respond to public health emergencies at the Federal, State, and local levels. We urge Congress to support the President's request by adding $50 million to this funding mechanism for fiscal year 2020.

Prevention is the best form of treatment. For this, ASTHO requests $170 million for the Prevent Block Grant. Programs funded by the Prevent Block Grant cannot be adequately supported or expanded through other funding mechanisms. States use these flexible dollars to offset funding gaps in programs that address the leading causes of death and disability. The success of the Prevent Block Grant is achieved by using evidence-based methods and interventions, reducing risk factors, leveraging other funds, and continuing to monitor and reevaluate funded programs.

CDC is not the only Federal agency that supports safety-net programs in States and territories. ASTHO is requesting $8.56 billion for discretionary funding for HRSA. HRSA administers programs that focus on improving care for tens of millions of Americans who are medically underserved or face barriers to needed care by strengthening the health workforce.

ASTHO is also encouraged by the Administration's plan to end the HIV epidemic in America. State and territorial health officials look forward to working with Federal and local partners across the country to bring effective strategies to scale. State, territorial, local, and tribal jurisdictions and our community-based organizations and healthcare partners must have the resources necessary to enhance and deliver these evidence-based public health interventions and not pull funds from other vital public health programs.

State and territorial health departments are on the front lines of responding to the current crisis in our country caused by substance misuse, addiction, and drug overdoses. ASTHO is appreciative of previous investments in public health toward this effort and supportive of an increase of $500 million, or a total of $2.4 billion, for the Substance Abuse Prevention and Treatment Block Grant at SAMHSA to sustain activities and continue the response to the opioid epidemic and substance abuse and misuse disorders more broadly.

Health indicator data from the territories and freely associated States (FAS) indicates that the health of these populations is far worse in comparison to the U.S. general population. Therefore, ASTHO requests that Congress fund a study conducted by the National Academies of Science, Engineering, and Medicine to better understand the health impacts of policy on the U.S. territories and FAS. The results of this research can guide investments, policy, and support and, ultimately, improve the health of those who reside in these insular areas.

Finally, if sequester cuts go forward, our public health system will have a diminished capacity to detect outbreaks; assure safe food, water, and healthcare facilities; and provide immunizations, and these are just a few examples. My colleagues and I are counting on you and other members of Congress to develop a bipartisan budget deal to address sequestration and raise the caps for non-defense discretionary spending. If we do not do this, we may not be able to ensure the kind of public health response we all need and expect nationwide.

[This statement was submitted by Michael Fraser, PhD, MS, CAE, FCPP, Chief Executive Officer, Association of State and Territorial Health Officials.]

Prepared Statement of the Association of University Programs in Occupational Health and Safety

On behalf of Association of University Programs in Occupational Health and Safety (AUPOHS), we respectfully request that the fiscal year 2020 Labor, Health and Human Services Appropriations bill include no less than $346,300,000 for the National Institute for Occupational Safety and Health (NIOSH), including not less than a $2 million increase over the fiscal year 2019 level for the Education and Research Centers (ERCs), the Agriculture, Forestry and Fishing (AFF) Program, and the Total Worker Health Program (TWH).

Occupational injury and illness create a striking burden on America's health and well-being. Despite significant improvements in workplace safety and health over the last several decades, 14 workers die daily from workplace injuries, and 145 people die from work-related diseases. Annually, 2.8 million workers are seriously injured on the job. One third of those injured workers require time off and 5,000 workers lose their lives to job injuries. According to the 2018 Liberty Mutual Workplace Safety Index, U.S. businesses spend more than $1.1 billion a week on serious, nonfatal workplace injuries.

These figures are especially tragic because many work-related fatalities, injuries and illnesses are preventable. To improve this situation effective, professionally directed, health and safety programs are required. Furthermore, by fostering workplaces that promote overall employee health and well-being, employers, employees, families, and communities benefit from improved productivity and reduced healthcare costs. NIOSH is the primary Federal agency responsible for conducting research and making recommendations for the prevention of work-related illness and injury and for promoting worker health and well-being.

As workplaces rapidly evolve, these changes continue to present new health risks to workers that need to be addressed through occupational safety and health research. For example, NIOSH is advancing the understanding of how emerging technologies such as robotics, nanotechnology, and advanced manufacturing can be managed to ensure safe operation. In addition, the opioid crisis is impacting millions of American workers and workplaces. NIOSH and the Centers developed a multipronged approach to identify high-risk work conditions leading to opioid misuse and to opioid use disorder. For example, NIOSH has focused on protecting responders from exposure to illicit fentanyl and how to best decontaminate workplaces. NIOSH is also the Federal agency that is charged with certifying and approving the respirators that are necessary to protect U.S. workers from inhalation exposures to numerous chemical and biological agents.

Through 18 university-based centers, the ERCs provide local, regional and national resources for those in need of occupational health and safety assistance—industry, labor, government, academia, non-governmental organizations and the public. Collectively, the ERCs provide graduate-level education in the occupational health and safety disciplines and offer professional workforce development training and research resources to every Federal Region in the U.S. Importantly, the ERCs play a crucial role in preparing a workforce of occupational safety and health professionals trained to identify and mitigate vulnerabilities to terrorist attacks and to increase readiness to respond to biological, chemical, or radiological attacks. Occupational health and safety professionals work with emergency response teams to minimize disaster losses, as exemplified by their lead role in protecting the safety of 9/11 emergency responders in New York City and Virginia. More recently in 2017, occupational health and safety professionals worked to minimize hazards among workers involved in clean up and restoration in the face of the extreme devastation caused by Hurricanes Harvey, Irma and Maria in Texas, Florida, Puerto Rico and the U.S. Virgin Islands.

NIOSH also focuses research and outreach efforts on the Nation's most dangerous worksites that often impact lives in more rural parts of America. The Centers for Agricultural Safety and Health were established by Congress in 1990 (Public Law 101–517) in response to evidence that agricultural, forestry and fishing workers suffer substantially higher rates of occupational injury and illness than other U.S. workers. According to 2018 bureau of labor statistics data, these agricultural workers are more than 6 times more likely to die on the job than the average worker. The AFF sector averages 540 fatalities per year resulting in the highest fatality rate of any employment sector in the Nation. Today the Agriculture, Forestry, and Fishing (AFF) Initiative includes ten regional Agricultural Centers and one national children's farm safety and health center.

The AFF program is the only substantive Federal effort to ensure safe working conditions in these vital production sectors. While agriculture, forestry, and fishing constitute some of the largest industry sectors in the U.S. (DOL 2011), most AFF operations are small: nearly 78 percent employ fewer than 10 workers, and most rely on family members, immigrants, part-time, contract and/or seasonal labor. Many of these agricultural workers are excluded from labor protections, including OSHA oversight, on the vast majority of American farms. More than 1 in 100 AFF workers incur nonfatal injuries resulting in lost work days each year. These reported figures do not even include men, women, and youths on the most dangerous farms—those with fewer than 11 full-time employees.

In addition to the harm to individuals and families, these deaths and injuries inflict serious economic losses including medical costs and lost capital, productivity, and earnings. The life-saving, cost-effective work of the AFF program is not replicated by any other agency. For example, State and Federal OSHA personnel rely on NIOSH research in the development of evidence-based standards for protecting agricultural workers and would not be able to fulfill their mission without the AFF program. Also, staff members of USDA's National Institute of Food and Agriculture interact with NIOSH occupational safety and health research experts in order to learn about the cutting-edge research and new directions in this area.

The AFF program activities have made demonstrated impacts on safety and health, as illustrated in the following examples. (1) AFF research showing that rollover protective structures (ROPS or rollbars) and seatbelts on tractors can prevent 99 percent of overturn-related deaths. (2) Developing training materials in partnership with producers to deliver evidence-based practical solutions that reduce exposures when handling pesticides and other farm chemicals among farmers workers and their children. (3) Partnering with fishing communities to develop and test improved life-jacket designs that are comfortable enough to wear while working, markedly improve chances of survival in the event of a fall overboard. (4) The Agricultural Centers have partnered with producers, employers, the Federal migrant health program, physicians, nurses, and Internet Technology specialists to educate farmers, employers, and healthcare providers about the best way to treat and prevent agricultural injury and illness. (5) The logging industry has a fatality rate more than 30 times higher than that of all U.S. workers. The Agricultural Centers have conducted ongoing studies and outreach efforts to ensure the safety of our Nation's 86,000 workers in forestry & logging.

NIOSH supports six Centers of Excellence for Total Worker Health (TWH) that conduct multidisciplinary research, test practical solutions, engage and educate employers and employees, with the goal of improving the overall safety, health, and well-being of the diverse population of workers in our Nation. The TWH Centers partner with government, business, labor, and community to improve the health and productivity of the workforce.

The TWH Centers' research, education, and outreach activities occur in workplaces, such as hospitals, factories, offices, construction sites, and small businesses, resulting in immediate and measurable improvements in health and safety. For example, most U.S. employers report that stress and mental health are major concerns for the effectiveness and well-being of their workforce. Work conditions including shift work, heavy lifting, and use of technology, can increase risk of injury and illness and impact worker health. Consequences can include higher rates of substance use, poor sleep, musculoskeletal disorders, poorer mental health, obesity, cardiovascular disease, and cancer. In turn, ill health, and chronic conditions impact job performance, increasing risk for serious injury, absenteeism, and reduced productivity.

TWH Centers conduct solutions-focused research in partnership with employers, to understand the underlying causes and then test and implement interventions to addressing these challenges. For example, TWH Centers have developed and evaluated interventions to reduce injuries and disease among workers in corrections, construction, emergency response/firefighters, healthcare, retail, food service, manufacturing, on-demand drivers, agriculture, and small businesses of all types. TWH Centers partner with small and large enterprises to address the needs of workers of all ages. These interventions have been shown to produce improvements in blood pressure, smoking rates, depression, stress, fewer lost work days due to injury, and savings for employers. In summary, the TWH Centers are an investment in the American economy, helping valued employees return home at the end of a productive day safe and healthier.

We urge you to recognize the important contribution of NIOSH, including the ERCs, the AFF Program, and the TWH Program to the health and productivity of our Nation's workforce. Thank you for the opportunity to submit testimony.

PREPARED STATEMENT OF BAKERRIPLEY

Dear Chairman Blunt:

BakerRipley supports a $6,000,000 increase in funding for the Administration of Community Living's Alzheimer's Disease Programs Initiative (ADPI) for a total of $29,500,000. This program supports and promotes the development and expansion of dementia-capable home and community-based long-term services and support systems in States and communities.

BakerRipley exists to keep Greater Houston a welcoming place of opportunity where everyone can earn, learn, belong and be well. BakerRipley's Health and Wellness Division promotes the dignity and independence of older adults and over the past thirty years, we have developed a reputation for innovation and excellence as we serve older adults with early to severe dementia and their caregivers. ADPI funds have allowed BakerRipley, in collaboration with the State of Texas and other regional partners, to lead in the development and implementation of programs focused on improving the recognition and response to older adults with dementia and their family caregivers.

IMPROVING LOCAL COMMUNITY RESPONSE

BakerRipley's first project funded through this program was the Houston Alliance to Address Dementia. This demonstration project aimed to address the dementia related knowledge and service gaps within Houston's aging and community service networks and provide better, more responsive services for those living with dementia and their families. The Houston Alliance to Address Dementia project investigated how Houston responds to individuals with dementia and their families and developed the foundation for further exploration to improve our response to this population. The Alliance recruited over 27 community and healthcare partners to better serve individuals affected by dementia and provided them with basic knowledge and tools they could use to connect families to local, proven services.

The project increased community knowledge of dementia and awareness about related resources and laid the groundwork for additional community level change. The project also prompted further conversation and exploration around the concept of "comprehensive care coordination" in better serving the needs of individuals living alone with dementia. The network that was developed continued after the ADPI funding ended, with more than 300 families per year directly connected with services that improve their quality of life.

IMPROVING STATE HEALTHCARE'S RESPONSE

Through the ADPI program, the State of Texas is improving supports provided to people with dementia who are dually eligible for Medicare and Medicaid. Building upon the learnings from the California Dementia Cal MediConnect Project and the Houston Alliance to Address Dementia project, Texas Health and Human Services, in partnership with BakerRipley, has engaged three health plans to improve their service delivery to this population, improving both the health and quality of life of the individual and the costs associated with care. Results of the ADPI-supported efforts include:

—Health plan adoption of validated cognitive impairment screening tools,
—Identification, assessment, support, and engagement of family caregivers; and,
—Adoption of a formal, warm handoff referral system to connect families and individuals to dementia-specific, community-based services.

The potential improvements to healthcare delivery to this population are appealing to the plans, as well as the State. Health plans have asked to continue this work past ADPI funding as they see the benefit both for their members and for their costs.

IMPROVING LOCAL HEALTHCARE RESPONSE

Most recently, BakerRipley received ADPI funding to expand upon the original Houston Alliance to Address Dementia project and focus on creating better connections to local healthcare organizations. Partnership with an established health system (Houston Methodist Coordinated Care, a local Accountable Care Organization) will allow improved care coordination and communication across community based and health service providers. The planned health system partnership will also create opportunity for improvements in dementia capability among the Houston aging and healthcare networks. Through the ADPI funding, specific cost data and health outcomes for individuals utilizing dementia-specific community services will be tracked and a case could be made in Texas for other healthcare payers, such as Managed Care Organizations to contract with these services as part of a cost reduction and quality of care improvement plan.

In summary, the Federal Alzheimer's program, now known as the ADPI, has been essential in Texas's State and local efforts to improve the quality of care, health outcomes, and costs associated with living with dementia. This funding has supported the development of programs with positive outcomes, but more importantly sustainability. We encourage the Labor Health and Human Services, Education, and Related Agencies Subcommittee to robustly fund this program. As the primary Federal program focused on the development of home and community-based long-term care services, funding of $29,500,000 will ensure that families impacted by dementia are supported and individuals remain safe.

I thank you for this opportunity to speak about the impact and importance of the Alzheimer's Disease Program Initiative and hope you continue to support this invaluable program.

Sincerely.

[This statement was submitted by Katie Scott, MPH, Senior Director of Dementia and Caregiver Support Services, BakerRipley.]

PREPARED STATEMENT OF JONATHAN AND LESLIE BARI

OVERVIEW

We are the Pennsylvania parents of a 6 year old son who was diagnosed in 2018 with Celiac Disease, a serious autoimmune disease that afflicts about 3 million Americans. We echo the recent testimony of Marilyn Geller, CEO of the Celiac Disease Foundation, to the U.S. House of Representatives Committee on Appropriations, Subcommittee on Labor, Health and Human Services, Education, and Related Agencies, when Geller stated, "If I leave you with one message today, it is that Celiac Disease is, in fact, a serious autoimmune disease that is not being taken seriously enough by our government."[1]

Today, many people have conflated the popular Gluten Free diet craze with the medically required Gluten Free diet for people with Celiac Disease. In 1952, it was first discovered that Gluten was the trigger of Celiac Disease.[2] To cure Celiac Disease, we need to fundamentally shift how our government leaders are educated on this disease. Why? Because the current research paradigm for Celiac Disease, one that has existed for many decades, has not delivered a cure or even a way to treat accidental ingestion of Gluten. There is no medicine or surgery available to treat Celiac Disease. To date, Celiac Disease research has produced only a single approved treatment—strict adherence to a lifelong Gluten Free diet with no excep-

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[1] Testimony of Marilyn G. Geller, CEO, Celiac Disease Foundation (Los Angeles, CA), to the U.S. House of Representatives Committee on Appropriations, Subcommittee on Labor, Health and Human Services, Education, and Related Agencies, April 9, 2019, https://celiac.org/april-2019-congressional-testimony-by-ceo-marilyn-g-geller/?

[2] "From Mussels to Bananas to Gluten: Celebrating Samuel Gee & Advances in celiac Disease Research," Beyond Celiac, August 27, 2018, https://www.beyondceliac.org/celiac-disease-news/celebrating-celiac-awareness-day-2018/.

tions! However, as Celiac Disease researchers have found, "[t]here is no such thing as a gluten-free diet because of the constant risk of cross-contact with gluten, and gluten is in 80 percent of our foodstuffs."[3] Additionally, for up to 30 percent of patients, diet alone is inadequate for remission in that it alleviates some symptoms, but does not heal and resolve intestinal damage caused by Celiac Disease.[4]

Anecdotally, we can attest to the treatment burden including the constant concern over cross contamination and inclusion of our son in life's numerous daily activities that involve food at home, at school (in Kindergarten) and away from home. Research has shown that the treatment burden of Celiac Disease is comparable to end-stage renal disease, and the partner (or parent) burden is comparable to caring for a patient with cancer.[5]

While the NIH purportedly makes allocation decisions on what diseases deserve Federal research funding based on disease burden and prevalence, NIH has seriously under-funded Celiac Disease over the last decade, even as the number of Americans diagnosed with Celiac Disease has kept increasing. Moreover, as detailed herein, NIH funding for Celiac Disease has significantly trailed comparable diseases that have the same or less prevalence, the same or less disease burden measurements, as well as more than one available treatment option. That is unacceptable! We need the U.S. Government, including the NIH and CDC, to step up and invest meaningful resources to find a cure to this debilitating disease that directly impacts the lives of 1 percent of Americans, in addition to their families and/or partners, on a daily basis. Celiac Disease is so serious that it is a "disqualifying condition" from service in the U.S. Military.[6]

SUGGESTED REPORT LANGUAGE TO THE NIH

We are respectfully asking that the Senate Appropriations Committee include the following Report Language to the National Institutes of Health:

"The Committee recognizes the serious issue of Celiac Disease which affects more than 3 million Americans, and that the number afflicted is growing. The Committee urges NIH to devote sufficient, focused research to the study of Celiac Disease. To date, NIH has examined symptoms of Celiac Disease and has not focused upon antecedent Celiac Disease and the autoimmune causation underpinning the affliction. Today, the only known treatment for this disease is a Gluten Free diet; but, recent private sector research has revealed that such a treatment is insufficient for many who suffer from Celiac Disease. Therefore, the Committee directs the Office of the Director to dedicate sufficient resources and robust investment toward multi-institute research to better coordinate existing research and focus new research efforts toward understanding causation and ultimately, finding a cure. The Office of the Director is directed to submit its plan for coordination and execution of this research to the Senate Appropriations Committee, including the funding and FTE associated with implementation of this plan, no later than 60 days after the date of enactment of this Act."

What is Celiac Disease?

Answer. An Invisible Illness with a Major Impact on People's Health

According to the University of Chicago Celiac Disease Center, "Celiac disease is an inherited autoimmune disorder that affects the digestive process of the small intestine. When a person who has celiac disease consumes gluten, a protein found in wheat, rye and barley [gluten helps food items maintain their shape, acting as a glue that holds food together[7]], the individual's immune system responds by attacking the small intestine and inhibiting the absorption of important nutrients into the body."[8] "Specifically, the tiny fingerlike protrusions called villi on the lining of the

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[3] Testimony of Marilyn G. Geller, April 9, 2019.

[4] Celiac Disease Foundation, https://celiac.org/about-celiac-disease/poorly-responsive-celiac-disease/.

[5] "Patient Perception of Treatment Burden is High in Celiac Disease Compared to Other Common Conditions," PMC, National Library of Medicine, National Institutes of Health, July 1, 2014, https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4159418/, and "What is Celiac Disease?", Celiac Disease Foundation, https://celiac.org/about-celiac-disease/what-is-celiac-disease/.

[6] U.S. Department of Defense, "DoD Instruction 6130.03, Medical Standards for Appointment, Enlistment, or Induction into the Military Services," Section 5.12.c.(3), May 6, 2018, https://www.esd.whs.mil/DD/.

[7] "What is Gluten?", Celiac Disease Foundation, https://celiac.org/gluten-free-living/what-is-guten/.

[8] University of Chicago Celiac Disease Center, Facts and Figures, https://www.cureceliacdisease.org/wp-content/uploads/341__CDCFactSheets8__FactsFigures.pdf.

small intestine are lost [damaged]."[9] 30–40 percent of Americans carry the genes for Celiac Disease, but only about 1 percent have Celiac Disease. No one knows what causes Celiac Disease to activate in some people, but not others. This is one of the key research areas that needs funding. Additionally, Celiac research has the potential to enhance understanding and improve therapies for other auto-immune conditions and unlock the mysteries of the microbiome which may enable treatment for a wide spectrum of diseases.

OUR SON'S POTENTIAL REACTIONS TO INGESTION OF GLUTEN

For all Celiac Disease sufferers such as our son, the Gluten protein (even in trace amounts such a crumb) can pose a severe health risk for:

A. Short-term sickness including abdominal pain, gas, diarrhea and/or vomiting; and

B. Long-term damage to the small intestine (which affects his ability to absorb nutrients required for proper growth and development), and an increased risk of other medical conditions including, but not limited to, auto-immune thyroiditis, liver disease, inflammatory bowel disease, osteopenia, osteoporosis, infertility, neurological conditions, cancer (lymphoma),[10] and immunological scarring.[11]

Food Allergies Significantly Impact Psychosocial Well-Being[12] of Children with Food Allergies

For all intents and purposes, Gluten is poison to our son's body, and it is analogous to the serious danger that peanuts pose to those who are afflicted with nut allergies. Eating Gluten does not initiate an anaphylactic cascade reaction in Celiac Disease patients. However, the ingestion of Gluten, even accidental ingestion of a trace amount of Gluten, can sicken and endanger (set back) the healing of a patient's small intestine enabled through his/her strict adherence to a Gluten Free diet, and/or trigger new damage to the small intestine that could take additional years to heal. There is no medicine available (i.e., epinephrine pen for nut allergies) to take to treat any accidental ingestion of Gluten.

According to the CDC, "Many studies have shown that food allergies have a significant effect on the psychosocial well-being of children with food allergies and their families."[13] According to the University of Chicago, "Living healthily with Celiac Disease requires skill in negotiating the everyday environment—especially for children and teens, where most positive social encounters, from school lunches to prom, is organized around food."[14]

Disparities Among Gastrointestinal Disorders in Research Funding From NIH

To understand and correct the historically inadequate NIH funding of Celiac Disease, it is instructive to read the peer reviewed academic analysis published in 2017 by the American Gastroenterological Association entitled, "Disparities Among Gastrointestinal Disorders in Research Funding From the National Institutes of Health." This analysis was written by some of the world's leading GI researchers, which found that, out of various Gastrointestinal Disorders, from 2011–2015:

A. "Celiac disease consistently received the lowest amount of NIH funding over the 5-year period, at approximately $3 million per year."

B. "Celiac disease consistently received the lowest amount of NIH grants, at approximately eight grants per year."

C. "Barrett's esophagus, with a prevalence of approximately 1 percent, received $64.1 million over the 5-year period. Celiac disease, with prevalence very similar to that of Barrett's Esophagus at approximately 1 percent, received signifi-

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[9] University of Chicago Celiac Disease Center, https://www.cureceliacdisease.org/overview/.

[10] Beyond Celiac, Fast Facts about Celiac Disease Infographic, www.beyondceliac.org , and https://www.beyondceliac.org/60forceliac/Fast-Facts-about-Celiac-Disease-Infographic/1448/.

[11] Celiac Disease Foundation, "Chronic Inflammation Permanently Alters Immune Cells in Celiac Patients," https://celiac.org/about-the-foundation/featured-news/2019/02/chronic-inflammation-permanently-alters-immune-cells-in-celiac-patients/.

[12] Beyond Celiac, Psychosocial Impacts of Celiac Disease Infographic, https://www.beyondceliac.org/60forceliac/Psychosocial-Impacts-of-Celiac-Disease-Infographic/1450/.

[13] U.S. Department of Health and Human Services, Centers for Disease Control and Prevention, "Voluntary Guidelines for Managing Food Allergies in schools and Early Care and Education Programs" (footnotes 39–45), https://www.cdc.gov/healthyschools/foodallergies/pdf/13_243135_A_Food_Allergy_Web_508.pdf.

[14] University of Chicago Celiac Disease Center, 2018 Year End Report, https://www.cureceliacdisease.org/wp-content/uploads/CdC_YearEnd_Report_18_WEB.pdf.

cantly less funding over the 5-year period at $15.4 million—the lowest amount of all the diseases studied."

D. "Although there is no global metric for disease importance, it is difficult to justify on medical and scientific bases a reason for such large and persistent funding differences. Although Crohn's disease has many available and emerging treatment options, celiac disease, for example, is more prevalent and has no current treatment available to patients beyond the burdensome gluten-free diet; however, celiac disease received only a small fraction of the funding that Crohn's disease received from the NIH over the 5-year period."

E. "In conclusion, NIH funding of GI diseases is not proportional to disease prevalence or mortality. These data further suggest that a few diseases, including IBS and celiac disease, are underfunded in comparison with other diseases, especially when the prevalence, burden, and available treatment options are considered. Plausible reasons for this disparity include varying numbers of established research programs to recruit young investigators, fewer grants submitted because of a lack of investigators in the field owing to poor funding, and narrow expertise of peer reviewers on NIH review committees. In contrast with disorders with low funding levels, ample public and private funding of Crohn's disease allows for excellent research, which in turn, favors more awards of research funding. This may seem circuitous; however, funding of Crohn's disease research provides an example of the way in which success breeds success." [15]

Research in Celiac Disease has lagged behind in the biomedical imagination of other more well NIH funded research diseases. This has been a vicious cycle adversely impacting the Celiac Disease research ecosystem whereby there have been fewer grant submissions, more limited interest among young researchers as well as very limited funding available from the private and philanthropic sectors. Public funding is perceived as validation of the seriousness of a disease and its research needs. Absent public funding validation, a vacuum is created, which causes private funding to be scarce. In contrast, the NIH funded Crohn's disease research model is an example of "success breeds success" that has created a positive feedback loop (network effects) with ongoing and meaningful government validation, more established research programs recruiting more young investigators, increased grant submissions, increased private sector funding, and increased philanthropic funding.

For fiscal year 2020, we are respectfully requesting that NIH model its funding of Celiac Disease research on its funding model and scale for research on Crohn's Disease. In spite of a lower number of disease specific mortalities as well as many available and emerging treatment options, Crohn's disease received about 40 NIH grants per year averaging about $16 million annually from 2011–2015, in comparison to Celiac Disease which received about 8 NIH grants per year averaging about $3.0 million annually from 2011–2015. In 2018, the NIH RePORT suggests that Celiac Disease research received a modest increase to 13 grants totaling approximately $4.7 million. In contrast, in 2018, NIH research funding for Crohn's disease encompassed 210 grants totaling $69 million.

Notwithstanding the Herculean efforts by some brilliant, small and under resourced research teams and advocacy groups, the paucity of NIH funding has created a vacuum and stifled innovation in the efforts to treat and cure Celiac Disease. This can change in fiscal year 2020 with meaningful NIH funding that validates research ready initiatives at multi-institute translational research centers including at the University of Chicago Celiac Disease Center, Celiac Disease Center at Columbia University, the Harvard Medical School Celiac Research Program and the Children's Hospital of Philadelphia Center for Celiac Disease.

PREPARED STATEMENT OF BETHANY CHRISTIAN SERVICES

FAMILY-BASED CARE AND POST-RELEASE SERVICES FOR UNACCOMPANIED CHILDREN

On behalf of Bethany Christian Services, we wish to submit outside written testimony on two important issues: the first is in support of "Family-Based Care and Post-Release Services for Unaccompanied Children" at the Office of Refugee Resettlement and the second is in support of "Infant Plans of Safe Care" at the Administration for Children and Families.

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[15] "Disparities Among Gastrointestinal Disorders in Research Funding From the National Institutes of Health," The American Gastroenterological Association, By: Emma Clerx, Harvard University; Sonia Kupfer, Celiac Disease Center at University of Chicago; and Daniel Leffler, North American Society for the Study of Celiac Disease, Beth Israel Deaconess Medical Center; September 4, 2017, https://www.gastrojournal.org/article/S0016-5085(17)36084-5/pdf.

At Bethany Christian Services, we believe that every child deserves to be in a loving family. We have a heart for children, and we equip families to be the answer for children in need. One of the ways we do this is by assisting unaccompanied refugee children reunify with family and friends in the United States. Bethany staff accomplishes this by providing in-home social services for unaccompanied children in Federal custody who have been identified as survivors of trafficking, fled community violence, have endured some type of abuse, or are being reunified with a caretaker. Bethany has been providing critical services to unaccompanied children for more than 40 years and since 2013, the organization has directly reunified more than 2,00 unaccompanied children with their family and assisted in reunifying more than 5,000 children.

In order to provide critical services for unaccompanied children, we recommend that the Committee provide an appropriation of at least $1,800,000,000 for this account in fiscal year 2020. We also recommend that the Committee prohibits the use of this funding to support forced family separation at the southern border, or increased use of large-scale institutional shelter facilities.

Furthermore, we ask that the Committee directs ORR to comply with its legally mandated duties as outlined in Section 426 of the Homeland Security Act of 2002, Section 235 of the William Wilberforce Trafficking Victims Protection Reauthorization Act of 2008, and the 1997 Flores settlement agreement. We recommend that ORR prioritize funding for expanded use of community-based residential care placements (including foster care and small group homes), as well as increased screening of sponsor placements prior to release (home studies) and social services following release (post-release services). Finally, we believe ORR should arrange for such services to be provided by NGOs with experience and expertise in working with these children.

While poverty, starvation, and a desire to reunify with family are ongoing motivations to migrate, increasing gang and domestic violence, coupled with a lack of government protection, remain the primary factors forcing children to flee Central America. In fiscal year 2018, 50,036 UC were referred to ORR custody and care. Robust funding is needed to ensure adequate care for UAC, many of whom have experienced persecution, abuse, trauma, or human trafficking.

Currently, there are significant but improving gaps in adequate home study and post-release service provision. Many UC have experienced trauma and prolonged family separation and yet, ORR provides family reunification services for less than thirty-two percent of children released from its care. These services offer things like home studies, in the most serious cases, to assess the safety and appropriateness of sponsors, as well as case-management or “post release services”. Proper funding for home studies and post-release services is the best way to assess the safety and appropriateness of sponsors and better protect children. Thus, we urge the Committee to direct ORR to prioritize funding for an increased percent of UC who are released from ORR’s care. Home studies and post-release services for UC help ensure safe family reunifications; mitigate the risk for family breakdown; facilitate children’s integration into their communities; assist with UC’s ability to comply with their immigration court proceedings. With these policy goals in mind, ORR should develop a spectrum of individualized service options for children released from its custody, including short-term intensive services, case management, and longer-term post-release services.

For those who remain in ORR custody, we encourage the Committee to direct ORR to place UC in community-based care, NGO child welfare shelters, and other child-friendly settings that reflect the best interest and needs of such children, including therapeutic placements and foster homes for young children and pregnant and parenting teens. We believe ORR should ensure sufficient bed space in such settings rather than placing children in large-scale institutional facilities.

INFANT PLANS OF SAFE CARE

Our second request for the LHHS Subcommittee for fiscal year 2020 is entitled “Infant Plans of Safe Care” and deals with the issue of caring for newborns impacted by the opioid crisis. We recommend that HHS prioritize funding for States that have high rates of neonatal abstinence syndrome and that partner with community-based organizations to deliver services that are consistent with Safe Care Plan to protect certain newborns and their caregivers.

The consequences of the opioid epidemic and parental drug use in recent years have caused thousands of children to be placed in foster care, overwhelming an already fragile system. We at Bethany Christian Services have over 75 years of experience serving vulnerable children and families, and we have found that nearly half of all infants adopted through our organization in 2018 had birthparents who engaged in both legal and illegal substance use.

Moreover, infants and toddlers are more likely than older children to enter foster care because of parental drug abuse (46 percent of removals vs. 30 percent of removals). In fact, nearly 105,000 children from birth to age 3 entered foster care in 2017. Experiencing maltreatment can negatively affect children at any age, but the implications for children in utero, infants, and toddlers are especially severe. Abuse and neglect during early developmental stages can permanently alter brain functioning and have long term behavior and cognitive ramifications.

Congress has taken strides to equip communities to combat the devastating impact of addiction on families through The Comprehensive Addiction and Recovery Act of 2016 (CARA) that directed child welfare agencies to ensure that Safe Care plans are put into place for the ongoing safety of the child as well as treatment needs of the caregiver. Congress also passed the SUPPORT for Patients and Communities Act last fall which provides additional resources to specifically address the impact of addiction on families.

We can do more to encourage States to formally partner with community-based organizations that have the expertise to deliver services and support to children and their families, consistent with Safe Care plans to be administered by the Department of Health and Human Service's Administration for Children and Families and its Children and Families Services programs. Specifically, we recommend that the Committee and HHS continue to emphasize the importance of Safe Care Plans and addressing the health and safety of the child, and any substance used disorder treatment for their caregivers.

The SUPPORT for Patients and Communities Act is now law, and it included additional authorizations for the Secretary to collaborate with and to support States in an effort to improve safe care plans for substance-exposed infants. As such, we urge Committee to direct the Secretary to prioritize funding for States that have high rates of neonatal abstinence syndrome and that partner with community-based organizations to deliver services that are consistent with the Safe Care Plan for these newborns and their caregivers. We also encourage you to direct the Administration for Children and Families to enhance their coordination with the States and continue working with those States with high rates of neonatal abstinence syndrome, and request an update on the work of the Secretary and ACF to implement these new policies.

Thank you for your continued leadership to help children and keep families together as we confront the effects of the opioid crisis, and I appreciate your consideration of Bethany Christian Service's Outside Written Testimony.

ABOUT BETHANY CHRISTIAN SERVICES

Bethany Christian Services was founded in 1944 in West Michigan and has grown to 120 branch locations in 35 States and 15 countries. The agency serves thousands of children annually nationwide in foster care programs and provides services across a continuum of care. Bethany's mission is to find a loving, permanent home for every child.

[This statement was submitted by Chris Palusky, President/CEO, Bethany Christian Services.]

Prepared Statement of Beyond Celiac

Celiac disease impacts an estimated 3.2 million Americans as well as their families and social support networks. It is a serious autoimmune disorder, a fact which is often misunderstood. Left undiagnosed or unmanaged, celiac disease can lead over time to lymphoma or other cancers, an impaired immune system, additional autoimmune problems and a range of life-threatening medical conditions. Adequate NIH funding is imperative as a means to address this important public health issue.

Because celiac disease—which is triggered by the ingestion of gluten in affected patients—is hereditary, many members and generations of the same family may show signs of gluten intolerance. For celiac disease patients, eating gluten creates an immune reaction in their bodies that damages the small intestine and interferes with the absorption of nutrients from food, leading to unintentional malnutrition. Today there is no medical treatment, and no cure. Currently, the only way to manage the high daily burdens of the disease and to minimize health risks is to initiate a life-long regimen of a strict gluten-free diet. For the tens of thousands of children affected—as well as for minority and lower-income families—this restriction can be especially difficult. For all celiac disease patients, finding food that is safe when traveling, eating out, eating at school or work or in other common circumstances is a significant challenge. For those with nonresponsive or refractory celiac disease, even perfection in diet maintenance will not restrain the disease. The diet is not enough.

Millions of Americans are facing serious, long-term health risks because of their celiac disease, and research funding levels and focus are woefully inadequate to address this significant healthcare issue. NIH funding of GI diseases, including celiac disease, is not proportional to disease prevalence or mortality. Patients need reliable treatments and a cure for celiac disease, progress that is only possible through a national commitment to the effort.

That commitment starts with appropriate NIH funding levels.

In a fall 2017 article in the renowned medical journal Gastroenterology, authors Emma Clerx, Sonia Kupfer and Daniel Leffler found that "NIH funding of GI diseases is not proportional to disease prevalence or mortality." They noted in particular that celiac disease "is underfunded in comparison with other diseases, especially when the prevalence, burden and available treatment options are considered."

Why is underfunding for celiac disease research an ongoing problem?

First, diagnosis rates (and overall awareness of the disease) are disturbingly low. An estimated 80 percent of people with celiac disease remain undiagnosed, partly because the symptoms of celiac disease cover such a broad spectrum. While an autoimmune reaction to gluten is the same for everyone with celiac disease, the symptoms can vary widely. Some patients show limited or no GI symptoms, while others have severe GI reactions. Some patients demonstrate mental issues, fatigue, skin rashes, reproductive health problems or other complications. Because celiac disease presents in so many different ways, some of which mimic other conditions, misdiagnosis remains prevalent. In fact, it takes the average celiac patient 6—10 years to secure an accurate diagnosis.

Second, many in the medical and funding communities underestimate the severity of the disease for patients over time. Celiac disease is a serious autoimmune condition. While we don't fully understand the nature of the connections with other autoimmune diseases or related medical issues, those connections are there. Patients with celiac disease may also be prone to arthritis, various cancers, liver disease, thyroid disease, Type 1 diabetes and other medical problems.

Third, those who allocate resources for research and disease management may mistakenly assume that a gluten-free diet is sufficient to counteract those adverse health outcomes. As explained above, the diet is virtually impossible to maintain, and even with perfect dietary compliance, medical complications of a serious nature still emerge over the long term for many celiac disease patients.

As a result of those three factors, fewer researchers have made career commitments to finding treatments and a cure for celiac disease. Fewer pharmaceutical companies are working in the space as well, at least partially because health insurers and other potential payers for treatments and medications (including Medicare and Medicaid) have low awareness of the serious nature of celiac disease and its long-term costs to the American healthcare system.

Increased NIH funding and focus can begin to turn the tide for more than 3 million Americans who are looking for answers to the serious issues living with celiac disease presents. It is not enough, however, just to increase NIH's funding overall. We need specific instructions to focus that funding on celiac disease when NIH allocates those funds to various organizations and research projects in the digestive disease fields.

With your funding support, we can begin to make progress. And, along with making advances toward a treatment and cure for celiac disease, those suffering with other autoimmune conditions may benefit from that research, as well.

In addition, Beyond Celiac respectfully asks that the Senate Appropriations Committee include the following Report Language to the National Institutes of Health:

> "The Committee recognizes the serious issue of celiac disease which affects more than 3 million Americans, and that the number afflicted is growing. The Committee urges NIH to devote sufficient, focused research to the study of celiac disease. To date, NIH has examined symptoms of celiac disease and has not focused upon antecedent celiac disease and the autoimmune causation underpinning the affliction. Today, the only known treatment for this disease is a gluten-free diet; but recent private sector research has revealed that such a treatment is insufficient for many who suffer from celiac disease. Therefore, the Committee directs the Office of the Director to dedicate sufficient resources and robust investment toward multi-institute research to better coordinate existing research and focus new research efforts toward understanding causation and, ultimately, finding a cure. The Office of the Director is directed to submit its plan for coordination and execution of this research to the Senate Appropriations

> Committee, including the funding and FTE associated with implementation of this plan, no later than 60 days after the date of enactment of this Act."

Beyond Celiac has been working for more than 15 years to support and advocate for the needs of the celiac disease community. Our early work was primarily in the realm of raising awareness, improving food labeling, and increasing gluten-free food availability and safety. As a critical first step, this work provided members of the celiac disease community with the best tools available at the time to better manage their health.

Beyond Celiac also has worked to raise awareness of the disease, increase diagnosis rates and build a community of mutual support by providing the latest information on living with celiac disease and updates on scientific advancements toward treatments and a cure. All of that work—as important as it has been—is not enough. We are now working as a catalyst to drive research toward effective treatments and a cure.

We stand ready to assist you with connections to our Scientific Advisory Council of experts or patients and patient advocates, as well as to provide whatever additional facts or resources you may need as you consider ways to support this important work.

With our sincere thanks.

[This statement was submitted by Alice Bast, CEO and Marie E. Robert, MD, Beyond Celiac.]

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 2020 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 2.8 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 twenty years the Federal TBI State Grant Program has supported State efforts to address the needs of persons with brain injury and their families and to expand and improve services to underserved and unserved populations including children and youth; veterans and returning troops; and individuals with co-occurring conditions.

In fiscal year 2009, the number of State grant awards was reduced to 15, later adding three more States, in order to increase each monetary award from $118,000 to $250,000. This means that many States that had participated in the program in past years have now been forced to close down their operations, leaving many unable to access brain injury care.

Increased funding of the program will provide resources necessary to sustain the grants for the 24 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 $12,000,000 for an additional 20 State grants, which would expand the total number of State grants to 44 bringing the total State grant allocation to just over $19,000,000.

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 and the National Concussion Surveillance System.

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 2.8 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 2018 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 2018 Reauthorization of the TBI Act, language was included authorizing CDC to create a National Concussion Surveillance System. Also, 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 2020 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 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 lifetime.

In addition, we respectfully request an increase of $4 million to the NIDILRR budget to continue to improve rehabilitation research.

We ask that you consider favorably these requests for the Administration for Community Living, the CDC, and the NIDILRR's TBI Model Systems of Care to further data collection, increase public awareness, improve medical care, assist States in coordinating services, protect the rights of persons with TBI, and bolster vital research.

If you wish any additional information, please contact Amy Colberg, director of government affairs at acolberg@biausa.org. Thank you for your continued support of individuals with brain injury and their families.

PREPARED STATEMENT OF THE BUREAU OF LABOR STATISTICS

Chairman Blunt, Ranking Member Murray, and members of the subcommittee, thank you for taking the time to consider my testimony on behalf of the Bureau of Labor Statistics. I speak to you as the Chair of the Friends of the Bureau of Labor Statistics (BLS), and as a former commissioner of BLS, regarding the fiscal year 2020 Appropriation for that agency. I urge you to provide an important efficiency-enhancing investment in America's data infrastructure by substantially increasing funding for BLS.

Accurate, timely, and readily available statistics are an essential public good in a free enterprise economy. Good statistics help private entities and governments make better decisions and investments, while bad or missing statistics can undermine efficiency in private markets and lead to bad choices that waste taxpayer dollars. Federal investment in the agencies that gather the most essential data for America's economic and social wellbeing have flatlined, and we are funding our Federal data infrastructure at irresponsibly low levels. The additional funding provided for BLS in fiscal year 2019 was very helpful, but we must increase the financial support of BLS to maintain American's position as the world's leading economy, and to advance the wellbeing of our children, families, businesses, and communities.

Funding BLS is an investment in efficient government. Public officials and policymakers need reliable data and tools to advance sound and responsible policies. As a producer of gold-standard data, BLS has a long history of independence and impartiality. Since its inception in 1884, BLS Commissioners have always supported the objective role of the agency. BLS follows all of the Office of Management and Budget directives to adhere to the objective presentation of facts, as well as explicitly protecting data integrity and transparency with respect to its methodologies and practices.

When urban and rural communities, families, and businesses of all sizes use BLS data they fuel economic development. Business can find the right workers, pay them competitive wages, while job seekers and students can make career decisions that will lead the right workers to the right employees.

For more than 125 years, BLS has produced vital information about jobs and unemployment, wages, working conditions and prices that serve as a key pillar of the data infrastructure of the Nation.

The increase in funding BLS received in fiscal year 2019 was beneficial, but cannot alone reverse nearly a decade of flat funding. BLS's purchasing power has fallen by nearly 14 percent since 2009. BLS has taken many steps to implement cost-saving measures to make the most of its budget. Currently, BLS is exploring options that include centralizing more data collection, moving to a multi-year sampling and collection protocols, using a combination of collected and modeled data, expanding web scraping techniques and autocoding. Even though these efforts have gone a long way, the current level of funding is not sustainable, and means BLS cannot adequately innovate and rise to new challenges in understanding our changing economy.

First, BLS cannot devote enough staff, data purchases, IT hardware and software to expand use of big data and to fully cover emerging economic trends, including the growing service sectors and the gig and digital economies. Our national data infrastructure continues to measure the manufacturing-based economy of the 20th century, often not registering the major transformations of recent decades and delaying implementation of modern "big-data" approaches that can reduce response burden and improve statistics. Without renewed investment in BLS, we all will be forced to address key economic issues with insufficient or outmoded data, which could result in costly policy or investment missteps. That poses serious risks to our workforce, our economy, and our society.

Second, short staffing risks serious errors or last-minute delays in major statistical releases. Less training, outdated equipment and software, and fewer back-ups raise risks from mistakes and unforeseen events. And these mistakes can be costly. A mistake of just 0.1 percent in the CPI would result in an over- (or under-) payment of almost $1 billion in annual Social Security benefits. Financial markets could also be roiled by sudden delays or large errors in jobs or inflation data releases. BLS staff works hard to make sure this does not happen, but the risk is growing.

With a return to full funding, BLS could reduce the risk of operational failure, accomplish many data improvements, and help ensure the wellbeing of American families.

Some key examples include:

- —Measure the Gig Economy. The May 2017 fielding of the CPS Continent and Alternative Employment Arrangement Supplement (CWS) was funding as a one-time reimbursable by the DOL Chief Evaluation Office. Without continual funding, the BLS cannot residing the questions in the CWS and other supplements to track emerging trends in the labor market. In addition, the employer perspective (incentives, type and degree of use) is still missing.
- —Modernize the Consumer Expenditure Survey. BLS is redesigning the Consumer Expenditure Survey to take advantage of new technologies that reduce the high respondent burden and improve data quality.
- —Measure employer-provided training. BLS last measured employer-provided training in 1995. Since then, our country has had no gold-standard information on whether employers are providing more or less training than in the past. What sort of training to they provide? To whom? How do they provide it? Gathering this type of data can help policy makers, educators and businesses understand and address our national skills needs.
- —Increase capacity for computationally intensive automation. Funds to enhance BLS hardware, software and expertise would advance BLS's ability to produce more detailed and improved products from its existing programs and administrative data. This capacity would increase the use of autocoding (to improve data quality and reduce reporting burden) and data matching, regional modeling, and merging.
- —Design surveys to answer new questions about our economy. BLS seeks to add the capacity to field survey modules that can provide gold-standard answers to urgent questions as they arise. These modules will address key questions as they arise, such as who employs gig workers, impacts of capital constraints, effects of natural disasters, etc.

Good data fuels the national economy and empowers good decisionmaking. It is essential to any effort to advance the well-being of our children as they prepare for the labor market, for families as they plan for their living arrangements, for small and large business owners as they plan for their future, and for policymakers as they evaluate programs and policies.

The statistics collected by BLS provide a stable foundation for decisionmaking. Every community, including businesses both large and small, relies on Federal data to fuel economic development. BLS's user metrics attest to the widespread usefulness of their data. The BLS website averages 19 million page views per month, as people access more than 107 million BLS data series.

Re-investing in BLS means the agency will continue to gather, analyze and share the trustworthy data needed for the evidence-based decisions that will move our economy forward. Please provide BLS with $655 million in fiscal year 2020 so that America's economy can work at its best for all Americans.

Thank you for your time and consideration of this important agency.

[This statement was submitted by Erica L. Groshen, Cornell University—ILR, Chair, Friends of the Bureau of Labor Statistics.]

PREPARED STATEMENT OF THE CAMPAIGN FOR TOBACCO-FREE KIDS

I am Matthew Myers, President of the Campaign for Tobacco-Free Kids. I am submitting this written testimony for the record to urge the Subcommittee to increase funding by $100 million for the Office on Smoking and Health (OSH) at the Centers for Disease Control and Prevention (CDC). By providing OSH with a fiscal year 2020 funding level of $310 million, CDC will be able to effectively address the rapid escalation of youth e-cigarette use, expand its highly effective Tips from Former Smokers public education campaign, and aggressively increase its efforts to assist populations and regions of the country with disproportionately high rates of tobacco use and tobacco-related disease and premature death.

Tobacco use remains the leading cause of preventable disease and death in the United States. More than 480,000 Americans die from tobacco use each year, and over 16 million Americans are currently living with a tobacco-caused disease.[1] Thirty-two percent of heart disease deaths, 30 percent of all cancer deaths, 87 percent

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[1] U.S. Department of Health and Human Services (HHS), The Health Consequences of Smoking—50 Years of Progress: A Report of the Surgeon General, 2014, http://www.surgeongeneral.gov/library/reports/50-years-ofprogress/.

of lung cancer deaths, and nearly 80 percent of all chronic obstructive pulmonary disease (COPD) deaths stem from tobacco use.[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]

Funding for CDC's Office on Smoking and Health has remained relatively flat since fiscal year 2014, not even keeping up with inflation, and is modest when compared to the estimated $170 billion in annual healthcare costs attributable to tobacco use.[4] Already forced to stretch its limited funding, OSH now faces a new challenge: soaring rates of e-cigarette use by youth. OSH needs additional resources to address this new threat to public health while continuing to reduce other forms of tobacco use, especially among populations disproportionately harmed by tobacco products.

Youth use of e-cigarettes skyrocketed throughout the U.S. in 2018—increasing by 78 percent among high school students and by 48 percent among middle school students in just 1 year. An estimated 20.8 percent of high school students (over 3 million students) were current users of e-cigarettes last year.[5] The FDA Commissioner and Surgeon General have both called youth e-cigarette use an "epidemic." The spike in youth e-cigarette use has resulted in the highest use of tobacco products by high school students in 14 years with more than 1 in 4 high school students using a tobacco product in 2018.[6] Further, as e-cigarette use has risen, progress in reducing youth cigarette use has stalled. There has been no significant change in the high school smoking rate since 2014, and the most recent CDC data from 2018 show a possible slight increase in cigarette smoking.[7] Alarmingly, research shows that e-cigarette use increases the risk of smoking cigarettes.[8]

The CDC's Office on Smoking and Health has a critical role to play in addressing the youth e-cigarette epidemic. The agency has extensive experience working with State and local health departments and the capacity to identify and implement effective prevention strategies designed specifically towards youth. An increase in funds would allow CDC to provide more resources to State and local health departments, educate students, parents and their communities about the risks of youth e-cigarette use, and develop and implement other strategies to protect kids.

In addition to the youth e-cigarette epidemic, there remains a great need to help adult tobacco users who want to quit. The vast majority of adult smokers started as youth, want to quit and wish they had never started.[9] The CDC's national media campaign, Tips from Former Smokers (Tips), has proven to be highly successful at helping smokers quit. The campaign features former smokers discussing the harsh realities of living with a disease caused by smoking and how current smokers can access evidence-based resources to assist them in quitting. Between 2012 and 2015, the campaign motivated over nine million smokers to make a quit attempt, helped

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[2] HHS, The Health Consequences of Smoking—50 Years of Progress: A Report of the Surgeon General, 2014; Centers for Disease Control and Prevention (CDC) Vital Signs, Cancer and Tobacco Use, Tobacco Use Causes Many Cancers," November 2016. https://www.cdc.gov/vitalsigns/pdf/2016–11-vitalsigns.pdf.

[3] HHS, The Health Consequences of Smoking—50 Years of Progress: A Report of the Surgeon General, 2014.

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

[5] Cullen, K, et al., "Use of Electronic Cigarettes and Any Tobacco Product Among Middle and High School Students—United States, 2011–2018," Morbidity & Mortality Weekly Report, 67(45): 1276–1277, November 16, 2018.

[6] Gentzke, Andrea S., et al., "Vital Signs: Tobacco Product Use Among Middle and High School Students—United States, 2011–2018Use of Electronic Cigarettes and Any Tobacco Product Among Middle and High School Students—United States, 2011–2018," Morbidity & Mortality Weekly Report, 68: 1–8, February 11, 2019.

[7] Gentzke, Andrea S., et al., "Vital Signs: Tobacco Product Use Among Middle and High School Students—United States, 2011–2018Use of Electronic Cigarettes and Any Tobacco Product Among Middle and High School Students—United States, 2011–2018," Morbidity & Mortality Weekly Report, 68: 1–8, February 11, 2019.

[8] Berry, KM, et al., "Association of Electronic Cigarette Use with Subsequent Initiation of Tobacco Cigarettes in US Youths," JAMA Network Open, 2(2), published online February 1, 2019; National Academies of Sciences, Engineering, and Medicine. 2018. Public health consequences of e-cigarettes. Washington, DC: The National Academies Press. http://nationalacademies.org/hmd/Reports/2018/public-health-consequences-of-e-cigarettes.aspx.

[9] U.S. Department of Health and Human Services (HHS), The Health Consequences of Smoking—50 Years of Progress: A Report of the Surgeon General, 2014,Babb, S., et al., "Quitting Smoking Among Adults—United States, 2000–2015," MMWR 65(52), January 6, 2017;Nayak, P., et al., "Regretting Ever Starting to Smoke: Results from a 2014 National Survey," International Journal of Environmental Research and Public Health, 2017; O'Connor, Richard J., et al., "Exploring relationships among experience of regret, delay discounting, and worries about future effects of smoking among current smokers." Substance Use & Misuse 51, no. 9 (2016).

over 500,000 smokers successfully quit, and saved at least 50,000 people from premature death.[10] The campaign is considered a "best buy" in public health, costing just $393 for each year of life saved.[11]

The Tips campaign has been enormously successful despite being on air for only part of the year. In its first 2 years (2012–2013), the campaign ran for 12 and 16 weeks, respectively. In 2018, the campaign ran for 25 weeks. With additional funding, the CDC could extend the number of weeks the campaign is on the air as well as the frequency with which the ads are run. Research has demonstrated that increased exposure to Tips ads leads to increases in intentions to quit and quit attempts.[12]

It is also important to address the growing disparity in tobacco use. Despite the progress that has been made in reducing tobacco use, certain populations and regions of the country face disproportionately high rates of tobacco use and tobacco-related disease and premature death. For example, Americans with lower levels of education and income, American Indians and Alaska Natives, lesbian, gay and bisexual adults, and adults with a mental illness all smoke at significantly higher rates than other Americans.[13] Despite initiating smoking later in life than whites, African Americans suffer from significantly higher rates of disease and death caused by smoking.[14]

With additional funding, CDC could provide targeted assistance to groups disproportionately harmed by tobacco use. By collaborating with State and local health departments and other community organizations, CDC could implement prevention and cessation programs tailored to resonate with and serve specific groups.

Given the harm that tobacco continues to inflict on the Nation's health, we were disappointed that the President's fiscal year 2020 budget request would eliminate the CDC's Office on Smoking and Health. While the budget proposes funding for a new block grant to States for chronic disease prevention, it does not require any of the funding to be spent on tobacco prevention and cessation activities and reduces overall funding for chronic disease prevention. This lack of funds would drastically undermine CDC's efforts to prevent youth from starting to use tobacco and to help adults to quit.

We urge the Subcommittee to increase funding for CDC's Office on Smoking and Health to $310 million. An additional $100 million would provide CDC with the resources it needs to increase funding to States and take other steps to address the epidemic of youth e-cigarette use, expand the highly successful Tips from Former Smokers media campaign, and provide targeted assistance to groups disproportionately harmed by tobacco use.

We appreciate the opportunity to highlight the important work of CDC's Office on Smoking and Health and the need to increase its funding.

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

PREPARED STATEMENT OF CANNONBALL KIDS' CANCER FOUNDATION

Chairman Blunt, Ranking Member Murray, and members of the Subcommittee thank you for your dedication to public health, and your continued efforts to appropriately invest in life-saving research to keep our Nation's health progressing forward. My name is Kelly King, and I am the Research Director at Cannonball Kids' cancer, a nonprofit foundation focused on funding innovative and accessible research for children fighting cancer and educating for change. On behalf of our foundation, the 40,000 children in the United States who are actively in treatment for pediatric

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[10] Murphy-Hoefer, Rebecca, "Impact of the Tips from Former Smokers Campaign on Population-Level Smoking Cessation 2012–2015," Preventing Chronic Disease Volume 15, E71, May 2018; Centers for Disease Control and Prevention (CDC), fiscal year 2017 Justification of Estimates for Appropriations Committees http://www.cdc.gov/budget/documents/fy2017/fy-2017-cdc-congressional-justification.pdf.

[11] Xu, Xin, et al., "Cost-Effectiveness Analysis of the First federally Funded Antismoking Campaign," American Journal of Preventive Medicine, 2014.

[12] Davis, Kevin C., et al. "Association Between Media Doses of the Tips From Former Smokers Campaign and Cessation Behaviors and Intentions to Quit Among Cigarette Smokers, 2012–2015." Health Education & Behavior (2017).

[13] CDC, "Tobacco Product Use Among Adults—United States, 2017," MMWR 67(44): 1225–1232, November 9, 2018.

[14] HHS, "Tobacco Use Among US Racial/Ethnic Minority Groups—African Americans, American Indians and Alaskan Natives, Asian Americans and Pacific Islanders, and Hispanics: A Report of the Surgeon General," 1998, http://www.cdc.gov/tobacco/data__statistics/sgr/1998/complete__report/pdfs/complete__report.pdf.

cancers and the nearly 2,500 families who will lose a child or adolescent to cancer in 2019, I am requesting that you continue to make pediatric cancer research a greater national priority. Specifically, I am asking the Subcommittee to ensure adequate funding for the NIH by rejecting the President's budget for this agency, and then directing the NIH to specifically fund the deadliest forms of childhood cancers with $25 million total in fiscal year 2020 funds appropriated to these line items.

I was privileged and honored to personally attend the fiscal year 2019 budget hearing for the National Institutes of Health of your sister Subcommittee. While I wasn't able to attend either hearing in person this year, I was able to view video coverage of both remotely. Through those hearings, I gained greater appreciation for some of our Nation's top priorities in healthcare, such as data aggregation, Alzheimer's, and internal controls at the NIH. I witnessed how integral this Subcommittee is to the upward trend of funding to the NIH and I respect your commitment to preserving that momentum, in spite of the President's recommendations for fiscal year 2020. It was also encouraging to hear childhood cancer mentioned by both Senator Moran and Senator Baldwin during their questioning. And, to witness Douglas Lowy, MD, Acting Director of the National Cancer Institute provide such a poignant response to Senator Moran.

As a result, I would like to commend the NIH and the Subcommittee for prioritizing childhood cancer this year! I believe that any mention of pediatric cancer during a Federal budget hearing is a step toward eradicating this horrific disease. So, thank you! However, these sentiments still must be translated to action, and there is much work to be done. That's why I'm submitting this written testimony. As the Subcommittee prepares its budget recommendations for fiscal year 2020, I want to ensure the members are acutely aware of the realities and statistics surrounding kids' cancers. I also intend to call your attention to what I believe was an omission in a previous bill that should be appropriately amended and financially supported.

The Recalcitrant Cancer Research Act: This Act of 2012, which President Obama signed into law in 2013 as part of the National Defense Authorization Act, defines recalcitrant cancers as those having a 5-year relative survival rate of less than 50 percent. It was championed by the Pancreatic Cancer Action Network (PanCAN) and calls on the National Cancer Institute (NCI) to develop scientific frameworks for the following cancers: pancreatic, lung, brain, esophageal, liver, ovarian, and stomach. The PanCAN website states: "When fully implemented, the statute will provide that much-needed strategic guidance and will also provide the accountability and congressional oversight to ensure that the resulting research stays on target."

However, no pediatric or adolescent cancers were named in the Act, nor have they received this type of individualized strategic thought and funding. As Dr. Collins noted in his remarks during the House hearing, "Although substantial progress has been made in the treatment of several types of childhood cancer, progress against other types has been limited." There are at least eight types of kids' cancers that have a survival rate of less than 50 percent including: anaplastic astrocytoma, diffuse intrinsic pontine glioma, glioblastoma, juvenile myelomonocytic leukemia, high-risk neuroblastoma, recurrent osteosarcoma, rhabdomyosarcoma, and diffuse anaplastic Wilms tumors.

National Prioritization in Action: With other diseases, national prioritization and subsequent designated Federal funding have helped our country make great strides in research, leading to revolutionary treatments and cures. Diabetes, specifically in the pediatric population, was discussed during the fiscal year 2019 hearing I attended. Before the discovery of insulin in the 1920s, children with diabetes rarely lived longer than 1 year. They also suffered side effects from their disease, such as blindness, loss of limbs, stroke, heart attacks, and kidney failure. Diabetes may not yet be curable and still requires daily maintenance, but only 1 percent of childhood deaths are now related to diabetes. And, as Dr. Collins mentioned, the NIH's prioritization of research for Sickle Cell Disease and Cystic Fibrosis have finally produced some significant gains in treating these diseases with clinical trials that are having phenomenal results!

For pancreatic cancer, the primary impetus for the Recalcitrant Cancer Research Act, there has been a 100 percent increase in median overall survival from Phase III clinical trials, a 900 percent increase in National Cancer Institute funding, and a 600 percent increase in the number of NCI-funded investigators studying pancreatic cancer, all since 1999. It's safe to say that the Recalcitrant Cancer Research Act has had a major, positive impact on these numbers, and that it will continue to help prioritize funding pancreatic cancer research, resulting in continued increases in survivorship.

Our Call to Congress: The Recalcitrant Cancers Research Act also "provides the NCI director with the authority to develop frameworks for other deadly cancers." This means any cancers added to the Act's list of "Recalcitrant Cancers" would also receive strategic guidance, added accountability, and congressional oversight. We've called on Congress to do just this!

I was on Capitol Hill with several of my colleagues in early March. During our visit, we were able to speak with 11 congressional offices, including seven in the Senate and four of whom sit on this very committee. Every one of those meetings was promising and productive as we explained the gap in the Recalcitrant Cancer Research Act. We committed to these offices that we would draft report language, asking Congress to urge the NCI to incorporate the deadliest forms of childhood cancers into the Recalcitrant Cancers category and to place a high priority on researching these cancers. This has since been completed and formally submitted to each of those offices.

The same language was also submitted to the House Labor, HHS, and Education Appropriations Subcommittee by my local Representative Stephanie Murphy and was adopted on May 8, 2019. Ms. Murphy has vowed to make this effort a high priority for her office and continue championing it for us. This progress is seen as a momentous victory by our team and for our cause. However, the language still must be adopted by your Subcommittee and translated to action.

How You Can Help: Now, we are respectfully asking the Subcommittee to ensure adequate funding for the NCI, with clear direction to the NCI Director to allocate a portion to these deadliest pediatric cancers. We believe this will give them the priority they deserve and help fiscally support the strategic plans that will be devised once they are classified as a Recalcitrant Cancer.

There has been much discussion about the Administration's budget providing $50 million for a data initiative that will be used to aggregate data and create a "federated, comprehensive, and shared resource to support childhood cancer research." This is honorable and necessary. So is the Childhood Cancer STAR Act that was passed and authorized last year, which appropriately requires funding for fiscal year 2020. However, a data bank is a long-term, complicated process that is only part of the steps needed to support the goal of developing new, more effective, and safer treatments for childhood cancers. We cannot wait on data to make treatment advances for our children. We should also be simultaneously investing additional funding into basic research and clinical trials for all types of pediatric cancer, but particularly those that should be considered Recalcitrant.

A Public Health Crisis: Gun violence remains a heated topic of discussion in our country. Every day, four children are deliberately killed with guns. This is unimaginable and tragic, but shockingly, this number is LESS than the number of deaths per day from pediatric cancer! Cancer continues to be the number one killer by disease of children and adolescents under the age of 19 in the U.S. In fact, it accounts for more deaths than all other childhood diseases combined! The average loss of life for a pediatric cancer patient is 71 years. And, our children are being treated with toxic chemotherapies designed for adults. Yet, as Dr. Lowy explained during the hearing, "One of the most important things to understand is that children who have cancer are not just small people who have adult cancer. But, childhood cancer is qualitatively different. Whereas adult cancer has many mutations, often there just are a few mutations that arise in children with cancer. In addition, while there is a tremendous amount of interest in cancer treatment for adult cancer, there is less involvement in the private sector. So the NCI has a particular obligation to do research in this area." However, the news media and the Subcommittee have not expressed outrage regarding pediatric cancer in the way they have for gun violence, nor have they called it a public health emergency. But, I will! This is a public health crisis and if the Appropriations Committee can designate funds specifically for gun violence research, then it also has the means to further support research into a disease killing more children each and every day. As the chairwoman said, "For all of our greatest health crises, we need our great health agencies to be fully involved in finding solutions."

Pediatric Cancer Survivorship: For those who survive childhood cancer, the Subcommittee should consider that survivorship for kids is measured the same as for adults. Five years from diagnosis is considered "surviving" for children. We often talk about children as young as 6 years old as "survivors." And if they then go on to die at age seven from their diagnosis, or the effects of their treatment, they are still classified as a survivor. Calling a deceased 7 year old a "survivor" hardly seems logical!

Additionally, these "survivors" will die earlier than their peers. As many as 95 percent of childhood cancer survivors are likely to experience at least one late effect of treatment, with one-third suffering life-threatening and chronic side effects and another third suffering moderate to severe health problems. Because kids with cancer are currently treated with drugs that were developed several decades ago for adults, many have substantial toxic side effects and research documents that they are very damaging to children's physical and intellectual development, leading to a diminished quality of life.

Finally, the Subcommittee should note that the incidence of invasive pediatric cancers is up 35 percent since 1975. According to the NCI, about 16,000 children and adolescents were diagnosed with cancer in 2018 (that is two classrooms full of students every school day).

It's Personal: There are more facts and statistics I could use to support my request. However, what matters most is that behind every statistic is a family who has been impacted by pediatric cancer. Many of the issues and concerns raised by the Subcommittee members during the hearing I attended were a result of their personal experiences or interactions with family members and constituents. I'd like to help make childhood cancer personal to you. My 3-year-old son, Nolan, died on April 1, 2017, from high-risk, Stage IV hepatoblastoma. After 15 months of surgeries and treatments, we were told there were no clinical trials available, and we were left to face our only option of palliative care. However, before we could begin navigating this "wait to die" approach, Nolan's heart stopped unexpectedly as a result of the toxicity from the 35-year-old chemotherapy drugs that failed to save him. Hepatoblastoma has a 20 percent survival rate when the disease has metastasized, yet it receives no dedicated NIH funding and there are no available treatment options for relapsed hepatoblastoma.

Summary: Ultimately, I commend the NCI, the Subcommittee, and Congress for their support of research into "recalcitrant cancers," the STAR Act, and potentially, the President's $50 million data initiative. But, I remain concerned that even with these efforts, the deadliest childhood cancers will remain under-researched and extremely difficult to treat, and no one among us should accept this as the status quo in the United States in 2019. We can do better, and one way we can begin to do so is by incorporating the deadliest kids' cancers into the Recalcitrant Cancer Research Act and then allocating appropriate funding to these cancers. I strongly urge the Subcommittee to appropriate $25 million in fiscal year 2020 funds to basic science and clinical trials for the deadliest forms of pediatric cancers. It may be too late for my son, Nolan, but I refuse to accept the past as the only course of action for the future.

[This statement was submitted by Kelly A. King, Research Director, Cannonball Kids' cancer Foundation.]

Prepared Statement of CAST

CAST is a non-profit organization that uses educational technology coupled with expertise in the learning sciences to ensure all learners can and do reach their full potential. Our primary lever for change is Universal Design for Learning (UDL), a framework pioneered at CAST that harnesses technology and instructional practices to remove barriers to learning in digital as well as physical settings. Our aim is to create a level playing field where all learners have equitable opportunities to succeed. UDL encourages the design of flexible learning environments that anticipate learner variability and provide alternative paths to success. UDL acknowledges that variation across learners is the norm rather than the exception regardless of an individual's age or disability status.

In fiscal year 2020, CAST requests the following:

—*U.S. Department of Education (ED).*—Fund all education programs at no less than the funding levels provided in the House fiscal year 2020 bill and prioritize UDL as a necessary component of all competitive grants made by ED.

—*U.S. Department of Labor (DOL).*—Require all Federal investments in training and employment to incorporate UDL as defined in section 103(a)(24) of the Higher Education Act,[1] and as referenced and endorsed as a best practice in the

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[1] § 103(a)(24), PL 110–315, Universal Design for Learning means "... a scientifically valid framework for guiding educational practice that—(A) provides flexibility in the ways information is presented, in the ways students respond or demonstrate knowledge and skills, and in the ways students are engaged; and (B) reduces barriers in instruction, provides appropriate accommodations, supports, and challenges, and maintains high achievement expectations for all students, including students with disabilities and students who are limited English proficient."

National Technology Plans of 2010 and 2016, as well as the National Ed Tech Developer's Guide of 2015.[2]

UDL's long history of striving for equity for all learners makes this level of investment logical. For nearly 30 years, UDL research, design and implementation has viewed universally designed technology and flexible digital materials as key components of instruction and interventions. The term "universally designed" (UD) refers to the design of built environments and products that make the world more accessible to individuals with disabilities. Speakerphones, curb cuts, and close-captioned television are all examples of universally-designed products-innovations that were originally developed to ensure access and use for individuals with disabilities but that benefit a variety of users. Universal Design for Learning extends the concept of UD to education and employment training by applying recent advances in the understanding of how the brain perceives and processes information to the design of curricula, instructional methodologies, assessment practices, and technologies and materials that can accommodate the widely variable abilities and needs of diverse learners.

In its 30-year history, CAST has brought UDL into K–12 schools, postsecondary settings and increasingly into career and technical education and the workplace. CAST's work is grounded in the vision of creating a world where "learning has no limits." CAST works in partnership with other organizations that also focus on improving access to and inclusion in K–12 schools, colleges, apprenticeships and employment. Research, development, and implementation of UDL is supported by multiple Federal agencies, State education systems, school districts, federally funded education and labor programs and private foundations. The Senate Appropriations Subcommittee plays a significant role in ensuring that programs through Title II of the Every Student Succeeds Act; the Higher Education Act, National Activities under the Individuals with Disabilities Education Act, State funding for the Strengthening Career and Technical Education for the 21st Century Act; Title II of the Higher Education Opportunity Act (HEOA); and Training and Employment for the DOL receive important funding in support of UDL.

There is a history of such funding in past appropriations bills. Substantial Federal investments in UDL began in the late 1990's and have steadily expanded. Over $150 million has been invested via ED's competitive grants programs to ensure that flexible and accessible learning materials are made available to all the Nation's K–12 students, and UDL has emerged as a key element in Federal education policy.[3] The Federal Government's investment in UDL is currently at work in improving universal design for people of all abilities in education. Recently, CAST's National Center on Accessible Educational Materials (AEM Center) was selected as the 2019 recipient of the Exemplary Program Award in Educational Technology by the American Council on Rural Special Education. The AEM Center provides resources and technical assistance to educators, parents, students, publishers, conversion houses, accessible media producers, and others interested in providing accessible education materials including open educational resources (OER) consistent with Federal requirements under the National Instructional Materials Accessibility Standard (NIMAS). CAST is helping teachers, administrators, assistive technology specialists, and curriculum creators at little or no-cost to improve and customize curricula to improve student access to materials and interoperability with student data, assistive technology and content management systems. This work significantly impacts access to education in K–16 settings.

Use of UDL in workforce development also continues to grow. With the pending requirement for States to develop and submit their CTE plans to ED, CAST is collaborating with the National Alliance for Partnerships in Equity by serving on their steering committee to advise on an initiative to broaden participation in STEM and CTE. In partnership with the National Science Foundation, six intermountain States will be brought together to scale up the use of evidence-based practices already shown to improve equity in CTE and increase access to STEM career training. Additionally, UDL is required in online and technology-enabled courses developed by grantees of the $2 billion Trade Adjustment Assistance Community College & Career Training grant program from DOL and is a foundational element of large-scale employment training initiatives like YouthBuild and Jobs for the Future. CAST's UDL in Higher Education[4] initiative prompts faculty designing career pathway training to plan for ways in which industry partners and instructors can collaborate on course development to create authentic, engaging scenarios so students learn skills in the context of a profession. CAST is also part of efforts to train CTE

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[2] See http://www.cast.org/whats-new/news/2016/udl-in-the-essa.html#.Wob36WbGzqQ.

[3] See: PL 110–315, PL 114–95.

[4] See http://udloncampus.cast.org/home#.Wte8tYjwY2w.

faculty in the application of UDL to help their students achieve educational and career goals.

The principle of equity for all learners is a major component of this success. As a flexible approach to addressing learner variability, UDL is organized around three core principles: (1) multiple means of representation, (2) multiple means of expression and action, and (3) multiple means of engagement. The UDL core principles consider the variability of all learners-including learners who were formerly relegated to the margins of our educational systems but now are recognized as part of the predictable spectrum of variation among individuals. These principles guide the design of learning environments that help lower barriers for diverse learners while maintaining high achievement expectations.

Powerful digital technologies applied using UDL principles enable easier and more effective customization of curricula for learners of any age or learning challenge. Advances in technology and the learning sciences have made "on-the-fly" individualization of curricula possible in practical, cost-effective ways, and many of these technologies have built-in supports, scaffolds, and challenges to help learners understand, navigate, and engage with the learning environment. While new technologies are not the only means of implementing UDL, their omnipresent and global use can free instructors to be creative and resourceful in designing flexible learning environments and providing additional challenges for advanced students or additional support to those that are struggling.

Increasingly, education and training programs of every level and type are incorporating significant digital and online components. Yet, despite the promise of flexibility, customized, one-off learning solutions, and anywhere/anytime educational opportunity often associated with digital learning, the reality is that the experience for many of today's learners has been at best underwhelming, and at worst detrimental. Leveraging the UDL framework is essential to mitigating the current impact of digital learning—especially for learners with challenges—whether they be based in poverty, language, disability, the aging process or something else. The population of digital learners that requires such training is predictably diverse and every federally supported training program must plan for that to ensure the effectiveness of these investments.

It's now time to bring UDL into the discussions focused on funding the Federal laws that: support people living and working with language barriers, low literacy or disability, including those who may experience disability as they age; and, to improve the workplace for any individual who may need accommodation so they can continue working. Why? Because, as the data show, one of modern science's greatest achievements is longevity—the unprecedented length of human lives today;[5] indeed, the average global life expectancy continues to climb.[6] Together, these statistics are compelling; however, they are made even more so when combined with these facts:

—One in five workers today is 55 or older; by 2024, that number will be one in four;[7]

—By 2024, nearly 25 percent of the labor force will include people who will be ages 55 and older-of whom about 13 million are expected to be ages 65 and older;[8] and,

—More than 80 percent of U.S. employers believe that workers aged 50 and more are a valuable resource and can offer knowledge, wisdom, and life experience.[9]

We also know that because people are living and working longer there is a desire to live and work independently for as long as possible.

The changing demographics in the U.S. make the Subcommittee's funding decisions incredibly important. Whether people continue to work full or part-time or are spending their time at home, UDL can play an integral role in generating the innovative, research-based solutions that individuals and families need to ensure the continuation of lifelong learning and productivity for aging adults, regardless of setting. Investments in UDL research-to-practice initiatives for both education and employment are essential.

It is imperative that all learners, including first-time career seekers and adults desiring new opportunities, have access to workforce development and career path-

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[5] D. Agarwal, "The Longevity Dividend: Work in an Era of 100–Year Lives," Deloitte Insights, March 28, 2018.

[6] World Bank, "Life Expectancy at Birth (Total Years)," 2017. Retrieved at: https://data.worldbank.org/indicator/SP.DYN.LE00.IN.

[7] M. Toossi, E. Torpey, "Older workers: Labor force trends and career options," Career Outlook, U.S. Bureau of Labor Statistics, May 2017. Retrieved at: https://www.bls.gov/careeroutlook/2017/article/older-workers.htm.

[8] Ibid.

[9] Transamerica Center for Retirement Studies, Baby boomer workers are revolutionizing retirement: Are they and their employers ready?, December 2014, p. 21.

way strategies and programs that are designed with the variability of their learning in mind. Continuing to invest in educational innovations that incorporate effective implementation of UDL while prioritizing the need to include UDL as part of the infrastructure of workforce and CTE faculty training makes sense. Anyone seeking new opportunities to expand their knowledge or improve their status of living or level of independence must have access to workforce development, career pathway strategies, and programs that are designed from the beginning with the variability of how their learning needs and potential living situation in mind. Beginning to promote investments in research-based innovations and technologies that incorporate effective use of UDL at work and at home simply makes sense.

CAST appreciates the opportunity to provide recommendations to fiscal year 2020. We urge the Subcommittee to make the following investment in UDL for all learners: (1) ED—fund all education programs at no less than the funding levels provided in the House fiscal year 2020 bill and prioritize UDL as a necessary component of all competitive grants made by ED. (2) DOL—require that all Federal investments in training and employment corporate UDL as defined in section 103(a)(24) of the HEA, and as referenced and endorsed as a best practice in the National Technology Plans of 2010 and 2016, as well as the National Ed Tech Developer's Guide of 2015.

PREPARED STATEMENT OF THE CDC COALITION

The CDC Coalition is a nonpartisan coalition of more than 140 organizations committed to strengthening our Nation's prevention programs. We represent millions of public health workers, clinicians, researchers, educators and citizens served by CDC programs. We believe Congress should support CDC as an agency, not just its individual programs. We are extremely pleased with the more than $8.22 billion provided to CDC in the House fiscal year 2020 Labor, Health and Human Services, and Education, and Related Agencies Appropriations bill. This total includes a transfer of $225 million from the HHS Nonrecurring Expenses Fund for one-time projects to improve CDC research and campus infrastructure. We urge the Senate to match the House funding level for CDC as you develop the Senate's fiscal year 2020 Labor, Health and Human Services, and Education, and Related Agencies Appropriations bill. We are grateful for the important increases provided for CDC programs in fiscal year 2019 and urge Congress to continue efforts to build upon these investments to strengthen all of CDC's programs. We oppose any effort to repeal or cut the Prevention and Public Health Fund which makes up more than 10 percent of CDC's budget and funds critical public health and prevention programs.

CDC serves as the command center for the Nation's public health defense system against emerging and reemerging infectious diseases. From aiding in the surveillance, detection and prevention of the Zika virus to playing a lead role in the control of Ebola in West Africa and detecting and responding to cases in the U.S., to monitoring and investigating disease outbreaks in the U.S., to pandemic flu preparedness to combating antimicrobial resistance, CDC is the Nation's—and the world's—expert resource and response center, coordinating communications and action and serving as the laboratory reference center for identifying, testing and characterizing potential agents of biological, chemical and radiological terrorism, emerging infectious diseases and other public health emergencies.

CDC serves as the lead agency for bioterrorism and other public health emergency preparedness and response programs and must receive sustained support for its preparedness programs. Given the challenges of terrorism and disaster preparedness we urge you to provide adequate funding for the Public Health Emergency Preparedness grants which provide resources to our State and local health departments to help them protect communities in the face of public health emergencies. We urge you to provide adequate funding for CDC's infectious disease, laboratory and emergency preparedness and response activities in order to ensure we are prepared to tackle both ongoing challenges and other public health challenges and emergencies that may likely arise during the coming fiscal year.

Injuries are the leading causes of death for people ages 1–44. Unintentional and violence-related injuries, such as older adult falls, firearm injury, child maltreatment and sexual violence, account for nearly 27 million emergency department visits each year. In 2013, injury and violence cost the U.S. $671 billion in direct and indirect medical costs. In 2017, opioids killed 46,700 individuals nationwide. CDC provides States with resources for opioid overdose prevention programs and to ensure that health providers to have the information they need to improve opioid prescribing and prevent addiction and abuse. In 2017, there were over 39,000 U.S. firearm-related fatalities. Congress should provide CDC with dedicated funding for firearm morbidity and mortality prevention research. The National Center for Injury

Prevention and Control must be adequately funded to conduct research, prevent injuries, and help save lives.

In 2016, over 635,000 people in the U.S. died from heart disease, the Nation's number one killer, accounting for about 23 percent of all U.S. deaths. More males than females died of heart disease in 2016, while more females than males died of stroke that year. Stroke is the fifth leading cause of death and is a leading cause of disability. In 2016, over 142,000 people died of stroke, accounting for about one of every 19 deaths. CDC's Heart Disease and Stroke Prevention Program, WISEWOMAN, and Million Hearts work to improve cardiovascular health.

More than 1.7 million new cancer cases and over 600,000 deaths from cancer are expected in 2019. In 2015 the direct medical costs of cancer was $80.2 billion. The National Breast and Cervical Cancer Early Detection Program helps millions of low-income, uninsured and medically underserved women gain access to lifesaving breast and cervical cancer screenings and provides a gateway to treatment upon diagnosis. The Colorectal Cancer Control Program focuses on improving screening rates among targeted, low-income populations aged 50–75 years in targeted States and territories through evidence-based interventions using partner health systems. CDC funds grants to all 50 States, DC, 7 Tribes and Tribal organizations, and 7 U.S. territories and Pacific Island jurisdictions to develop comprehensive cancer control plans, bringing together public and private stakeholders to set priorities and implement cancer prevention and control activities to address each State's particular needs.

Cigarette smoking causes more than 480,000 deaths each year. CDC's Office of Smoking and Health funds important programs and education campaigns such as the Tips From Former Smokers campaign which has already helped more than 500,000 individuals quit smoking and millions more to make a serious quit attempt. We must continue to support this and other vital programs to reduce the enormous health and economic costs of tobacco use in the U.S.

Of the more than 30 million Americans living with diabetes, more than 7 million cases are undiagnosed. Each year, about 1.5 million people are newly diagnosed with diabetes. Diabetes is the leading cause of kidney failure, nontraumatic lower-limb amputations, and new cases of blindness among adults in the U.S. The total direct and indirect costs associated with diabetes were $327 billion in 2017. We urge you to provide adequate resources for the Division of Diabetes Translation which funds critical diabetes prevention, surveillance and control programs.

Obesity prevalence in the U.S. remains high. More than one-third of adults are obese and 18.5 percent of children ages of 2 to 19 are obese. Obesity, diet and inactivity are cross-cutting risk factors that contribute significantly to heart disease, cancer, stroke and diabetes. The Division of Nutrition, Physical Activity and Obesity funds programs to encourage the consumption of fruits and vegetables, encourage sufficient exercise and develop other habits of healthy nutrition and physical activity and must be adequately funded.

Arthritis is the most common cause of disability in the U.S., striking more than 54 million Americans of all ages, races and ethnicities. CDC's Arthritis Program helps address this growing public health challenge and works to improve the quality of life for individuals affected by arthritis and we urge you to support adequate funding for the program.

CDC provides national leadership in helping control the HIV epidemic by working with community, State, national, and international partners in surveillance, research, prevention and evaluation activities. CDC estimates that about 1.1 million Americans are living with HIV with 15 percent undiagnosed. Prevention of HIV transmission is the best defense against the AIDS epidemic. Sexually transmitted diseases continue to be a significant public health problem in the U.S. Nearly 20 million new infections occur each year. STDs, including HIV, cost the U.S. healthcare system almost $16 billion annually.

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

CDC's REACH program helps communities address serious disparities in infant mortality, breast and cervical cancer, cardiovascular disease, diabetes, HIV/AIDS and immunizations by supporting community-based interventions and we urge the committee to provide continued funding for these important activities.

CDC oversees immunization programs for children, adolescents and adults, and is a global partner in the ongoing effort to eradicate polio worldwide. Childhood immunizations provide one of the best returns on investment of any public health program. For every dollar spent on childhood vaccines to prevent thirteen diseases, more than $10 is saved in direct and indirect costs. Over the past 20 years, CDC estimates childhood immunizations have prevented 732,000 deaths and 322 million illnesses. We urge you to provide adequate funding for the Section 317 Immunization program. Congress must support efforts to stop current vaccine-preventable disease outbreaks, including the current measles outbreaks in several States, and prevent more from occurring.

Birth defects affect one in 33 babies and are a leading cause of infant death in the U.S. Children with birth defects that survive often experience lifelong physical and mental disabilities. Approximately one in six U.S. children is living with at least one developmental disability and one in four adults live with a disability. The National Center on Birth Defects and Developmental Disabilities conducts programs to prevent birth defects and developmental disabilities and promote the health of people living with disabilities and blood disorders.

Programs within CDC's National Center for Environmental Health work to control asthma, protect from threats associated with natural disasters and climate change, reduce, monitor and track exposure to lead and other environmental health hazards and ensure access to safe and clean water. Increased funding for NCEH's environmental health prevention activities will help reduce illness, disease, injury and even death.

In order to meet the many ongoing public health challenges facing the Nation, including those outlined above, we urge the Senate to match the House funding level of more than $8.22 billion for CDC as you develop the Senate's fiscal year 2020 Labor, Health and Human Services, and Education, and Related Agencies Appropriations bill.

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

PREPARED STATEMENT OF THE CELIAC DISEASE FOUNDATION

Chairman Blunt, Ranking Member Murray, and distinguished Members of the Subcommittee, thank you for the opportunity to provide written testimony. Below is the oral testimony I provided to the House Appropriations Committee Subcommittee on Labor, Health and Human Services, Education, and Related Agencies on April 9, 2019.

"My name is Marilyn Geller and I am the Chief Executive Officer of the Celiac Disease Foundation—an organization devoted to finding the cure for celiac disease.

If I leave you with one message today, it is that celiac disease is, in fact, a serious autoimmune disease that is not being taken seriously enough by our government.

Celiac disease is one of the world's most common genetic autoimmune diseases. Approximately 40 percent of us carry the genetic marker and about 1 percent of us actually develop celiac disease. Yet, this is nearly double the number of people with Crohn's disease and ulcerative colitis combined, and nearly triple the number of those with Type 1 Diabetes.

And, regrettably, researchers are finding that the disease prevalence is doubling approximately every 15 years, making it a public health epidemic.

It is estimated that only 20 percent of the 3 million Americans with celiac disease have been correctly diagnosed. The other 2.4 million continue to suffer and have no idea why. In celiac disease patients, gluten, a protein found in wheat, barley and rye, triggers an immune response leading the body to attack the small intestine.

This intestinal damage causes more than 200 debilitating symptoms. Moreover, gluten ingestion for people with celiac disease causes permanent immunological scarring, doubles the risk of heart disease, and acts as a carcinogen, quadrupling the risk of small intestinal cancers.

My son Henry is why I am sitting before you today. Henry was ill from birth and was suffering for reasons the best specialists in Los Angeles could not determine. He suffered from unbearable pain, can't get out of bed fatigue, endless stomachaches, headaches, medications, medical procedures, and at the lowest point, in middle school, would say to me, "Mommy my brain is telling me to kill myself again, and I don't want to, please help me." It was a fifteen-year ordeal until a doctor finally ordered a blood test for celiac disease. From that point on, it's been personal for me.

Strict adherence to a gluten-free diet is the only available treatment. But, as our celiac disease researchers agree, "there is no such thing as a gluten-FREE diet" because of the constant risk of cross-contact with gluten, and gluten is in 80 percent of our foodstuffs.

—And, in our medications—an issue that Ranking Member Cole and Congressman Tim Ryan are working with us to combat.

—Thank you, Congressman Cole... your leadership on this issue means so much to our work.

In closing, I traveled here today because we need celiac disease to be recognized as an important threat to the health of our citizens by the U.S. Government, including and especially by the NIH, the FDA, the CDC, and CMS.

—Celiac disease research receives virtually no investment from the private sector, and little to no resources from NIH, especially when compared to diseases with similar impact.

—This gap is something Leslie Williams, Founder and CEO of ImmusanT and leader in celiac disease research knows all too well. She states:

> "Sadly, Marilyn's story is all too common. Drug development is built on a foundation of basic science, and without public funding of basic research, drug development is severely hindered. Moreover, public funding is perceived as indicative of unmet need and the seriousness of a disease. Without the attention that comes with public finding, private funding can be scarce—we have lived this. The paucity of funding for celiac research is shocking especially when comparing it to other conditions that are much less common, arguably less severe AND have available treatments. Moreover, celiac research and treatment has the potential to guide understanding and improve therapies for other autoimmune conditions. Public funding is needed to support celiac research; private funding will follow in a more substantial way."

Let me reiterate the seriousness of this disease.

—The lifetime burden of the gluten-free diet is perceived by patients to be second only to end-stage renal disease, and by caregivers, comparable to caring for a patient with cancer.

—Our diagnosed patients report that they miss, on average, 23 days of work and school annually, resulting in excess utilization of our healthcare resources.

—Despite what you might see in popular media, celiac disease is not a fad. It is not a punchline. Americans are dying because we haven't paid sufficient attention to this disease.

Thank you for your time today and thank you for anything this distinguished Subcommittee can do to assist us in this fight to end this serious disease."

As a result of my testimony, the following was included in the House Committee on Appropriations Report:

Celiac Disease. The Committee encourages NIH to devote sufficient, focused research to the study of Celiac disease, including the autoimmune causation underpinning the affliction. Today, the only known treatment for this disease is a gluten-free diet; but, recent public and private sector research has revealed that such a "treatment" is insufficient for many who suffer from Celiac disease. Therefore, the Committee urges NIAID to support new research to better coordinate existing research and focus new research efforts toward causation and ultimately, a cure of this disease. NIAID is encouraged to coordinate with other Institutes and Centers as appropriate and to submit its plan for coordination and execution of this research to the Committee on Appropriations no later than 90 days after enactment of this Act.

I respectfully request that this distinguished Subcommittee include the same or similar language in its Report. On behalf of the 3 million Americans afflicted with celiac disease, their loved ones, employers, co-workers, teachers, and fellow students, I thank you for your efforts to combat this serious, and potentially treatable, autoimmune disease.

For additional information, please contact: Julia McBeth, Director of Research and Advocacy, Celiac Disease Foundation at julia.mcbeth@celiac.org.

[This statement was submitted by Marilyn G. Geller, CEO, Celiac Disease Foundation.]

PREPARED STATEMENT OF THE CHILD CARE ACCESS MEANS PARENTS IN SCHOOLS

Dear Chairmen and Ranking Members,

As organizations committed to promoting the postsecondary success of college students with children, we are writing to express our strong support for increasing funding for the Child Care Access Means Parents in Schools (CCAMPIS) program to $150 million—the amount needed to provide child care support to approximately 2 percent of Pell-eligible student parents of children ages 0–5. The CCAMPIS program provides vital support for the participation and success of low-income parents in postsecondary education through the provision of campus-based child care, which is widely recognized as one of the most important supports for parenting college students. The $35 million increase in CCAMPIS funding in fiscal year 2018 that was sustained in fiscal year 2019—$50 million for both fiscal years—was a much-needed and appreciated boost in funding to help address the care needs of students with children. In light of the additional cap relief provided by the fiscal year 2019 budget deal, tripling this amount to $150 million in the Labor-H appropriations bill would go even farther to ensuring more parenting college students receive the child care assistance they need to be successful in college.

Nearly 4 million college students are parents of dependent children, representing more than one in five undergraduates in the United States. Many of these student parents are balancing college and parenting without the support of a spouse or partner, with 1.7 million women in college are single mothers.

Student parents, and particularly those who are single, face acute financial and caregiving demands that can complicate their ability to persist to graduation. Student parents are more likely than other students to live in poverty, to have no resources to devote to college costs, and to incur substantial student debt-due in large part to the high cost of child care. Student parents also spend significant time providing care, with 21 percent of community college students spending 20 hours or more per week caring for dependents, according to the 2018 Community College Survey of Student Engagement.

Access to affordable child care is one of the most important supports that can help student parents succeed in college. Campus-based child care, however, has been declining in recent years, most dramatically at community colleges where the largest numbers of student parents are enrolled. Research suggests that access to campus child care can play a significant role in student parents' ability to persist in college and graduate with a degree; without it, they are often forced to drop out before they have completed their educational programs. In 2018, 27 percent of community college students reported that they are likely or very likely to drop out of school due to their caregiving responsibilities.

The CCAMPIS program is the only Federal program dedicated solely to providing child care assistance for students in postsecondary settings. It helps meet the high demand for low-cost child care, enabling student parents to persist in and complete postsecondary credentials, which are critical to their families' economic well-being and are associated with a range of important multigenerational benefits. Continuing to increase the program's funding to serve a larger percentage of Pell-eligible students with young children would allow the program to reach tens of thousands more students, greatly improving their chances of postsecondary success.

For these reasons, we express our strong support for increasing funding for the Child Care Access Means Parents in Schools (CCAMPIS) program to $150 million in the fiscal year 2020 Labor-H appropriations bill.

Sincerely,

Center for Law & Social Policy (CLASP)
Child Care Aware of America
Early Education Action League
Higher Learning Advocates
JFF
NASPA—Student Affairs Administrators in Higher Education
National Center for Student Parent Programs
National Skills Coalition
New America Education Policy Program
SHP
Women Employed
Young Invincibles

Childcare Centers from Over 25 Institutions, Including:
Alverno Early Learning Center
Ashburnham Westminster Extended Day Program
Associated Students Child Development Center, San Jose State University
Campus Center for Young Children
College of Lake County Children's Learning Center
College of the Redwoods
East Tennessee State University
Florence Darlington Technical College
LaGuardia Community College Early Childhood Learning Center Programs, Inc.
Margaret's House @ RIT
Mesa Community College Children's Center
Monroe Community College (SUNY)

Mount Wachusett Community College
Northeast State Community College
Northwest Child Development Center
Partners for Education at Berea College
PERG at Endicott College
Precious Memories Childcare/CCAMPIS
Rio Hondo College Child Development Center
San Juan College Child & Family Development Center
Santa Monica College
Student Parent HELP Center, University of Minnesota—Twin Cities
The Evergreen State College
University of New Mexico

PREPARED STATEMENT OF THE CHILDREN'S HOSPITAL OF PHILADELPHIA

Dear Honorable Congressmen and Congresswomen,

We write this letter today as pediatricians to ask you to address the lack of funding for a very important health issue that affects millions of Americans—celiac disease and gluten sensitivity. Celiac Disease is a serious autoimmune disease that affects 1 percent of the population worldwide. It is caused by exposure to the food protein gluten which is found in such grains as wheat, barley and rye. Celiac Disease causes inflammation and intestinal damage, leading to symptoms such as abdominal pain, constipation, poor growth, anemia, headaches, vitamin deficiencies and bone disease. If left undiagnosed or untreated, this disease can increase susceptibility of other autoimmune diseases such as diabetes as well as adult risk for coronary artery disease, infertility and small bowel cancers.

Currently, there are no pharmacotherapy options available for celiac disease and the only therapy remains a strict gluten elimination diet. Dietary changes may seem simple, but the need for 100 percent elimination of gluten from the diet is challenging and isolating. There is a real risk of cross-contamination from packaged foods, restaurants and school cafeterias that families struggle daily. Even eating a few crumbs of gluten can cause intestinal damage and setback disease healing. Hence, families and children avoid eating out and feel an increased anxiety about food that can impact a child's normal development. Nearly half of children with celiac disease exhibit anxiety and physical symptoms from a heightened fear of gluten. Even when they attempt strict adherence to a gluten-free diet, 70 percent of children continue to be accidentally exposed to gluten, putting their long-term health at risk. The same challenges are seen in adults with celiac disease. A study in 2014 by Shah et al found that celiac disease patients report a higher treatment burden and reduced quality of life as compared to patients with other diseases such as gastroesophageal reflux disease, hypertension, diabetes and congestive heart failure.

As the leaders of the Center for Celiac Disease at the Children's Hospital of Philadelphia, we encounter many of the symptoms and challenges of celiac disease in infants and children. We have cared for more than 3,500 patients and families with celiac disease, wheat allergy and gluten-sensitivity in the past 5 years. These children can no longer suffer in silence, which is why we need to invest in research and development of new therapeutics in celiac disease.

Our clinical physicians and scientists at the Children's Hospital of Philadelphia are prepared to lead the way in scientific research to improve diagnostics and discover medical treatments for children, but this simply cannot be a reality without national funding and support of our political leaders. This is why we plead that you work with your colleagues in the Appropriations Committee to increase research support of this devastating autoimmune disease by increasing funding for Celiac Disease to at least $15 million for the upcoming 2020 fiscal year. These funds will be used for immunology and intestinal microbiome research to initiate collaborative Celiac Disease drug trials. Millions of Americans nationwide will be forever grateful to your initiative in helping to find a cure.

If you need any additional information regarding celiac disease and how we can work together to cure autoimmune conditions and improve children's health, each of us are happy to meet with you in person. Thanks again for your time and support.

Sincerely.

[This statement was submitted by Lisa Fahey, MD, David Piccoli, MD, Co-Director, CHOP Celiac Center Chief, and Arunjot Singh, MD, MPH, Division of Gastroenterology.]

PREPARED STATEMENT OF THE CHRISTOPHER & DANA REEVE FOUNDATION

Thank you for this opportunity to submit testimony in support of an appropriation of $8,700,000 for the Paralysis Resource Center (PRC) within the Administration for Community Living (ACL).

I am proud to speak in support of the 1 in 50 individuals living with paralysis in the United States, who rely on programs like the Paralysis Resource Center to live independent and empowered lives. The Reeve Foundation has operated the Paralysis Resource Center for 17 years, competing in a rigorous, competitive application process every 3 years for renewal of this grant. For fiscal year 2020, we request level funding of $8.7 million for the Paralysis Resource Center.

Despite its tremendous success, the PRC has been recommended for elimination in the President's budget for the third year in a row. The proposed justification is that its initiatives could be carried out with other existing funding streams that support services to those with varying disabilities. However, the PRC is the only program of its kind that directly serves individuals living with spinal cord injury, MS, ALS, stroke, spina bifida, cerebral palsy and other forms of paralysis or mobility impairment. Attempting to replicate the PRC's already established and thriving programs would take years and result in greater costs-precisely the opposite of what the Administration's budget aims to do.

When my father, Christopher Reeve, was paralyzed from the neck down due to a spinal cord injury in 1995, our family found ourselves in total darkness as to what to do next. There was no phone number to call for guidance or help. There were no experts reaching out to connect us to rehabilitation facilities or discuss how we could support his return home and ongoing well-being. There was certainly no promise that an individual living with that level of spinal cord injury could lead a full and active life. Yet instead of accepting that life with paralysis would be full of limitations, my father dreamed of a brighter future.

That was the genesis of the Christopher & Dana Reeve Foundation: my father's dream to elevate the needs and rights of the 5.4 million Americans living with paralysis. But my father was far from alone. The real drive behind the Paralysis Resource Center came from my stepmother, Dana. As a caregiver herself, she knew that paralyzed individuals and caregivers around the country need a centralized place to call for resources and expertise.

Since the PRC opened its doors in 2002, it has served as a free, comprehensive, national source of informational support for people living with paralysis and their caregivers.

The PRC's Core Programs

Funding made available for the Paralysis Resource Center by the Subcommittee currently supports five core program areas, or pillars. These are:

(1) Information Specialists. One of the PRC's most essential functions is the team of certified, trained Information Specialists who provide personalized support on how to navigate the challenges of life with paralysis. This team of experts, some living with paralysis themselves, are often the first call for individuals who are newly injured or diagnosed.

To date, the PRC's team of Information Specialists and peer mentors has provided direct counseling and information to over 105,000 people. We have distributed over 200,000 copies of our Paralysis Resource Guide, which is a staple in hospitals and rehabilitation facilities across the country.

(2) Peer & Family Support Program. A second pillar of the PRC is our Peer & Family Support Program. This program is born of the idea that the best source of knowledge is experience—and that peer-to-peer connections empower not only the newly-paralyzed individual, but also the mentor. Through the PRC, more than 380 peer mentors have been trained and certified in 40 States. These individuals have mentored 12,057 peers, including nearly 1,500 caregivers. Mentors are well equipped to offer help on a variety of topics including: transitioning home from a rehab center, researching job or educational opportunities, getting information on health and secondary conditions, coping with the responsibilities and emotional challenges of being a caregiver, building confidence and motivation, and navigating local, State, and national resources.

(3) Quality of Life Grants Program. Our third pillar, the Quality of Life Grants Program, operates at the community level to fund nonprofit initiatives in all 50 States and territories. Since 1999, the Quality of Life Grants Program has leveraged over $24 million dollars in support of over 3,000 projects in every State. This program has supported employment trainings and accessible transportation; established adaptive sports programs and camps for

children; improved access to buildings, playgrounds and universities; helped individuals learn how to manage their financial well-being, and provided support services for veterans. Critically, these programs use the public attention that comes from receiving funding affiliated with the Reeve Foundation and the PRC to raise additional funds in their communities, creating a powerful return on investment.

The organizations funded by the PRC break down barriers and create life-changing opportunities. For example, a grant to Paraquad, Inc. in St. Louis, Missouri, supported career leadership training for high school students with disabilities. Grants to Bridge Disability Ministries in Bellevue, Washington helped fulfill unmet medical equipment needs for people living with paralysis. The Lakeshore Foundation in Birmingham, Alabama was able to provide family recreation and sports for paralyzed and severely injured U.S. Military members and veterans through the organization's "Operation Down Home" program. The Veterans Venture Program in Killington, Vermont, helped injured veterans return to the outdoor sports they loved. Grants to the Children's Hospital of Wisconsin supported the improvement of the developmental outcomes for children with impaired mobility. These are but a handful of examples.

(4) Military & Veterans Program & Multicultural Outreach Program. The PRC's Military and Veterans Program provides dedicated resources to help individuals navigate military and civilian benefits and programs as they reintegrate into their communities. The PRC also facilitates a Multicultural Outreach Program that is designed to engage and support underserved populations such as ethnic minorities, older adults, low income earners, and LGBTQ individuals.

(5) ChristopherReeve.org. One of the most challenging aspects about living with paralysis is combating feelings of isolation and exclusion, especially for those who are unable to leave their homes due to physical and societal barriers. The Reeve Foundation's website, ChristopherReeve.org, provides an online resource hub that attracts close to two million visitors per year. Earlier this year we launched Reeve Connect, a fully redesigned online community. This interactive safe space offers individuals, family members and caregivers a way to ask questions, share their experiences, and connect with those who understand the everyday and intimate realities of paralysis.

The Value of Integrated Services

There are many examples in which an individual living with paralysis has not only participated in one program of the PRC, but has benefitted from the integrated nature of our services. In 2011, Erin Cobb from North Carolina was a victim of domestic violence when her ex-husband, a former Marine suffering from severe PTSD, attempted to murder her and then killed himself. Erin was shot twice in the face and neck and, after almost losing her life due to life-threatening infections, emerged paralyzed to an unknown and terrifying new normal. Erin did not receive the information or care she needed and was dangerously close to losing her life. Four months after the injury, her mother, Janet, contacted the Reeve Foundation through the Paralysis Resource Center, where she was connected to comprehensive materials and personalized guidance. Erin and Janet finally felt as if there was hope and a path forward. Erin was able to access appropriate rehabilitation and surgical reconstruction, and ultimately returned to work. Janet left her career and became Erin's full-time caregiver, ensuring that Erin is able to live as independently as possible. Janet credits the PRC with saving Erin's life. She has become one of the PRC's most dedicated advocates, serving on our Military and Veterans Programs (MVP) Council and volunteering as a peer mentor and ambassador for the MVP and Peer & Family Support Program.

Janet and Erin's journey—from PRC clients, to program participants, to peer mentors and ambassadors—shows the value of the integrated services made possible by the scope, scale and stability of the PRC.

The Importance of Federal Funding

I would like to close my remarks by emphasizing why Federal funding for the PRC is so important. A resource center that is relied on by millions of Americans affected by paralysis needs consistent, regular funding. Because many individuals living with paralysis have to attend rehabilitation clinics and/or draw on other resources from out of State, nationwide expertise is required. To get the benefit of investing in a centralized hub of information, we need to promote and deliver these services at scale. Simply put, Federal funds are essential for this valuable, life-changing resource to work.

Federal funding for the PRC is also a good investment. Our resources help people to adapt their homes, gain the tools they need to return to their communities, and eventually to work. The programs funded by the PRC allow individuals to make better informed decisions, access resources, and minimize dangerous and costly secondary health conditions while leading active lives.

My father once said, "Hope is like a lighthouse," helping individuals who are lost in the darkness find their way. But like a lighthouse, hope must be built on a solid foundation. The resources, support and community created by the PRC are the foundation for hope for millions of individuals affected by paralysis around the country.

On behalf of the board, leadership, advocates of the Christopher and Dana Reeve Foundation, and the hundreds of thousands of individuals whom we are able to serve, I thank the Subcommittee for its ongoing support, and for your consideration of this request.

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

PREPARED STATEMENT OF CLAUSEN HOUSE

Mr. Chairman, Ranking Member Murray, I am Ms. Jaynette Underhill, Executive Director of Clausen House-a non-profit organization founded in 1967 in Oakland, California that is the longest-serving, multi-programmatic organization accessed by adults with intellectual and developmental disabilities (IDD) in Alameda County, California. The overarching mission of Clausen House is to create opportunities for individuals with intellectual and developmental disabilities to gain competency, identify and realize their goals and aspirations, develop relationships and join the community with increasing command over their own lives.

I am truly honored to have this opportunity to present written testimony in support of an enhanced fiscal year 2020 budget for the Administration for Community Living (ACL); and to urge the Subcommittee to include language in its Committee Report that would pave the way for funding of a Pilot Program proposed by Clausen House to establish an Integrated Senior Day Program and Adult Transition Services Program in fiscal year 2020.

First, the Administration for Community Living is the Federal Government's preeminent advocate for older adults, people with disabilities and their families and caregivers, and provides grant and other support to, among other entities, organizations or networks of organizations to help older adults and people with disabilities to find support and services to help them with community living and integration. ACL also funds research and development to generate new knowledge and promote its use to enhance community living and integration for citizens with disabilities. Last year, at our urging, the Senate Appropriations Committee included language on page 163 of S. Rept. 115–289 urging ACL to partner with HUD, CMS and other Federal agencies to support efforts to provide specialized housing for individuals with developmental disabilities-services that Clausen House provides in Alameda County, California.

The ACL also funds "Developmental Disabilities Projects of National Significance" through grants and contracts, to demonstrate innovative methods to support the independence, productivity and integration into the community of persons with development disabilities.

In short, the goals, objectives and authorized activities of the ACL mirror the priorities of Clausen House and the broad range of unique integrated, comprehensive services that it has been providing to citizens with intellectual and developmental disabilities for over a half century.

However, the President's fiscal year 2020 budget for the ACL makes significant reductions in programs that are of special importance to Clausen House and other entities that provide the kind of IDD services that we provide to our constituents in California. For example, the President virtually eliminates the Projects of National Significance program, cutting the program from $12 million in fiscal year 2019 to $1 million next year. He also dramatically cuts the National Institute on Disability, Independent Living and Rehabilitation Research-the agency's primary grant-making office-by over 17 percent from $109 million to $90 million in fiscal year 2020. Overall, the President's budget for Disability Programs, Research and Services is cut by over 19 percent below current levels.

We urge the Subcommittee to restore these programs to at least the appropriations levels that were approved in fiscal year 2019.

Second, consistent with the mission and programs of the Administration for Community Living, Clausen House is recommending Committee Report language that would allow the ACL to fund a unique, two-part adult services Pilot Program-a Pilot

Program that will directly benefit citizens with intellectual and developmental disabilities to remain independent, continue to live in specialized housing settings, and enhance service offerings to facilitate independence, care and quality of life for these important constituents of Clausen House.

As part of the Pilot Program, and to augment existing efforts to promote independence and integrated activities for seniors with intellectual and developmental disabilities, Clausen House is proposing the establishment of a comprehensive Integrated Senior Day Program Initiative for IDD citizens in Alameda County and elsewhere. The innovative design and delivery of this program initiative for senior citizens with intellectual and developmental disabilities would create a model that does not exist anywhere else in the County.

The Clausen House model envisions a full range of valuable activities for IDD seniors, including but not limited to music, arts and crafts, gardening, exercise programs, walking, dancing and other community integration activities that will be tailored specifically to address the unique needs of an aging IDD population.

Furthermore, the Clausen House program envisions an ongoing effort to form partnerships with Schools of Social Work among colleges and universities to access the tremendous resources that those institutions of higher education could provide to IDD citizens, including services from licensed social workers, faculty, and Masters of Social work students seeking field experience among our constituencies.

Clausen House also would use any funding that might be made available through the ACL budget to sustain its programs through reimbursements from the State, and through long-term partnerships with Health Maintenance Organizations, healthcare providers operating under provisions of the Affordable Care Act, and partnerships with skilled nursing facilities and behavioral health experts.

This unique approach to further integrating our IDD citizens into the fabric of the larger community has the potential to be a transformative model for adult service delivery in that it is designed to fill a gap in service; enhance quality of life outcomes; create efficiencies in service delivery and be carried out with low administrative overhead costs. Initial estimates are that, depending on funding, this innovative program would immediately be able to provide services to at least 45 new IDD senior citizens in fiscal year 2020.

One of the systemic challenges facing the intellectual and developmental disabilities community is the dearth of critically-needed services to provide to young adults as they "graduate" from 18 year olds, into the early ages of adulthood (19–25). The need is great to provide "transition" programming from adolescence/young adults into adulthood.

As part of the proposed Pilot Program, the gap in services to this special group of citizens is proposed to be filled through an innovative Adult Transition Services Program Initiative that will be specifically designed to serve IDD citizens between the ages of 19 and 25 years of age. The need for adult transition services to this age group is significant as the number of individuals with intellectual and developmental disabilities within Alameda County and elsewhere is increasing dramatically each year.

Specifically, as part of the Pilot Program, the Clausen House Adult Transition Program Initiative envisions the establishment of an innovative in-service design and delivery system that does not exist. Funding ultimately provided by ACL would allow Clausen House and others, to develop this desperately needed adult transition program initiative-an initiative that can be sustained after an initial ACL investment, by other funding available through Regional Centers that are under contract with the State Department of Developmental Services (DDS); private pay for services; non-profit foundations; and partnerships with existing Transition Age Youth services in the State.

This component of our proposed Pilot Program is consistent with Clausen House's 50-year track record of providing integrated, comprehensive services to adult IDD citizens and would provide a significant, transformational program to bridge the major gap between services for adolescents and adults with intellectual and developmental disabilities. Again, this innovative Adult Transition Services Program Initiative is at the core of Clausen House's mission to provide comprehensive services designed to allow IDD adults to be independent, healthy, safe and able to enjoy a sustained quality of life.

In closing, Mr. Chairman and Ranking Member Murray, we believe that the Clausen House-proposed Pilot Program will allow entities like our organization to dramatically enhance the delivery of services to citizens with intellectual and developmental disabilities in Alameda County and nationwide. On its website in describing its Consumer Choice and Control responsibilities, the Administration for Community Living says, among other things:

"Older adults and people with disabilities are unique individuals, and the help they may need is unique, as well. These programs focus on helping ensure that the preferences and the needs of older adults and people with disabilities are at the center of the system of services and supports that enable them to live the lives they want to live."

Clausen House concurs and embraces these responsibilities within our mission. To these ends, we firmly believe that our proposed Pilot Program is directly aligned with the ACL mission and is truly a Project of National Significance that meets the requirements of the programs, projects and activities that are funded each year under this critically important ACL program.

[This statement was submitted by Ms. Jaynette M. Underhill, MA, Executive Director, Clausen House.]

PREPARED STATEMENT OF THE COALITION FOR CLINICAL AND TRANSLATIONAL SCIENCE

FISCAL YEAR 2020 APPROPRIATIONS RECOMMENDATIONS

- —CCTS joins the broader medical research community in asking Congress to provide the National Institutes of Health (NIH) with at least a $2.5 billion funding increase for fiscal year 2020, to bring total agency funding up to a minimum of $41.6 billion annually.
  - —Please provide the Clinical and Translational Science Awards (CTSA) program at the National Center for Advancing Translational Sciences (NCATS) with at least a $25 million increase for fiscal year 2020 to bring total support for the program up to a minimum of $585 million in annual, dedicated line-item funding.
  - —Please provide the Cures Acceleration Network (CAN) at NCATS with $100 million in dedicated funding for fiscal year 2020, to bolster total support for the program and to ensure that adequate resources are available to ensure notable progress.
  - —Please provide the Institutional Development Awards (IDeA) program and the Research Centers in Minority Institutions (RCMI) program at NIH with meaningful funding increases for fiscal year 2020.
- —CCTS joins the broader medical research community in asking Congress to provide the Agency for Healthcare Research and Quality (AHRQ) with a $122 million increase for fiscal year 2020 to bring total funding up to $460 million annually.
  - —Please continue to support research training and career development activities at NIH and AHRQ to ensure that the next generation of clinical and translational researchers is well-prepared.
- —Please work with your colleagues to reauthorize the Patient Centered Outcomes Research Institute (PCORI) to ensure important research can continue in fiscal year 2020.

Chairman Blunt, Ranking Member Murray, and distinguished members of the Subcommittee, thank you for considering the views of the clinical and translational research community as work on fiscal year 2020 appropriations. Moreover, thank you for providing NIH with a significant $2 billion funding increase for fiscal year 2019, for notably increasing CTSA funding and improving stewardship of dedicated resources, and for supporting AHRQ.

ABOUT THE COALITION FOR CLINICAL AND TRANSLATIONAL SCIENCE

The Association for Clinical and Translational Science, the Clinical Research Forum, the CTSA PIs, and the related stakeholder community work together through the Coalition for Clinical and Translational Science (CCTS) to speak out with a unified voice on behalf of the clinical and translational research community. CCTS is a nationwide, grassroots network of dedicated individuals who seek to educate Congress and the administration about the value and importance of clinical and translational research, and research training and career development activities. Our goals are to ensure that the full spectrum of medical research is adequately funded, the next generation of researchers is well-prepared, and the regulatory and public policy environment facilitates ongoing expansion and advancement of the field of clinical and translational science.

ABOUT THE CTSA PROGRAM AND THE FULL SPECTRUM OF MEDICAL RESEARCH

The CTSA Program was established to disseminate medical and population health interventions to patients and populations more quickly, and to enable research teams, including scientists, patient advocacy organizations and community members, to tackle system-wide scientific and operational problems in clinical and translational research that no one team can overcome in isolation. The CTSA program honors the promise of the Cures Act by improving research infrastructure and accelerating the rate at which breakthroughs in basic science are translated to innovations with a tangible benefit to patients.

The goals of the CTSA program include; (1) train and cultivate the translational science workforce, (2) engage patients and communities in every phase of the translational process, (3) promote the integration of special and underserved populations in translational research across the human lifespan, (4) innovate processes to increase the quality and efficiency of translational research, particularly of multisite trials, (5) advance the use of cutting-edge informatics.

The CTSA Program supports a national network of "hubs" at academic research centers across the country that work collaboratively to improve the translational research process to get more treatments to more patients more quickly. The hubs collaborate locally and regionally to catalyze innovation in training, research tools and processes. Roughly 58 medical research institutions across the Nation currently receive CTSA program funding, and these hubs work together to speed the translation of research discovery into improved patient care. Resources appropriated to these hubs allow the network to expand to include additional sites, advance science, and directly invest in the health workforce of the communities where they are located.

The full spectrum of medical research includes basic research, pre-clinical research, clinical research, clinical implementation, and public health. In order to maximize efficiency and patient-centeredness, this research must be done collaboratively and in a systematic way. This team-science approach focuses on outcomes and patient/health system benefits, rather than the advancement of science for the sake of science. There are numerous examples of the success of this approach, including the community's annual awards for the "Top 10" projects, which can be viewed here. In fact, the project studying culturally component healthcare delivery using community barber shops in Los Angeles, was even praised by NCATS in the Center's fiscal year 2020 budget request.

Finally, the appropriations committees have included meaningful committee recommendations in the past that have facilitated meaningful advancements for the full spectrum of medical research, the CTSA program, and career development for early stage investigators and we hope similar recommendations will be provided for fiscal year 2020.

RECENT COMMUNITY SUCCESSES

—Ananth Shalev, a UAB investigator, has demonstrated that taking a commonly used blood pressure medicine (verapamil) helps to preserve pancreas (beta cell) function in Type 1 diabetes and thereby leads to reduced insulin need and significantly better diabetes control. This novel, inexpensive, well tolerated treatment when applied to Type 1 and Type 2 diabetes will address a major health problem, especially prevalent in the Southeast.

—Steve Rowe, a UAB investigator, has led a team to demonstrate that the newly developed medicine, ivacaftor, is not only a breakthrough treatment for the pulmonary problem in cystic fibrosis but can also be used to treat adult chronic obstructive pulmonary disease. COPD is a major cause of morbidity and mortality and ivacaftor can significantly enhance lung function, patient functional status and quality of life.

—Researcher at Einstein-Montefiore found that Preeclampsia is more prevalent and severe in women with African ancestry, most likely because of genetic factors. The research team has been investigating a variant of the gene encoding apolipoprotein L1 (APOL1), which was previously shown to confer a high risk of kidney disease in black Americans. Studying two independent populations of pregnant black women from the Bronx and from Tennessee, they found that preeclampsia was associated with the APOL1 high-risk genotype. Interestingly, it was the genotype of the fetus, not the mother, which mattered.

A TIMELY NOTE FROM THE CTSA COMMUNITY

Thank you again for your leadership on medical research funding issues and for your ongoing support for the Clinical and Translational Science Awards (CTSA) program. We reach out to you today on behalf of the Association for Clinical and

Translational Science, Clinical Research Forum, the Coalition for Clinical and Translational Science, and the CTSA Program PIs, to reiterate the importance of maintaining the line-item protecting CTSA program funding within the Senate's fiscal year 2020 Labor-Health and Human Services-Education Appropriations Bill or corresponding Committee Report.

The community deeply appreciates the inclusion of $17 million in additional CTSA funding through LHHS appropriations efforts for fiscal year 2019. Just as important though was the traditional utilization of line-item funding and the inclusion of strong committee recommendations (most notably during the fiscal year 2018 process) regarding stewardship of dedicated CTSA resources and oversight of the program. These recommendations and related efforts have been crucial to ensuring that CTSA funding provided by Congress is invested in local hubs to advance ongoing efforts, and that the program overall can continue to grow in scope to meet its mission.

The community remains concerned that any flexibility in annual CTSA funding will facilitate a reduction in resources that will diminish support for established institutions and eliminate opportunities for meritorious emerging research centers working to join our national network. As you consider fiscal year 2020 appropriations for NIH and medical research, please continue to invest in the CTSA program with a proportional increase, but more importantly, please ensure that the funding line-item for CTSAs is maintained and supported with an allocation of at least its current fiscal year 2019 level of $560 million.

Thank you for your time and your consideration of our request. Please consider the community and its local representatives a resource on this topic, and let us know if we can provide any additional information or answer any timely questions.

[This statement was submitted by Harry P. Selker, MD, MSPH, Chairman, Clinical Research Forum.]

Prepared Statement of the Coalition for Health Funding

The Coalition for Health Funding—an alliance of 95 national health organizations representing more than 100 million patients and consumers, health providers, professionals and researchers—welcomes the opportunity to submit this statement for the record about the importance of health funding. Together, our member organizations speak with one voice before Congress and the administration in support of federally funded health program with the shared goal of improved health and well-being for all. Each member organization has their own funding priorities within the Department of Health and Human Services (HHS), but we all believe that to truly improve health, you need strong, sustained, predictable funding for all Federal agencies and programs across the public health continuum.

HHS agencies have different roles in addressing our Nation's mounting health demands, but they are all interconnected. For example, investment in medical research at the National Institutes of Health (NIH) is important, but on its own won't improve health. You need the Food and Drug Administration (FDA) to approve new treatments. You need the Centers for Disease Control and Prevention (CDC), Health Resources and Services Administration (HRSA), Substance Abuse and Mental Health Services Administration (SAMHSA), and Indian Health Service to ensure we have qualified health professionals who can move discoveries into healthcare and public health delivery, support Americans while they're awaiting new cures, and prevent them from getting sick in the first place. You need the Agency for Healthcare Research and Quality (AHRQ) to provide evidence on what treatments work best, for whom, in what circumstances. And you need the Administration for Community Living to support those who are aging and those who have disabilities—as well as their caregivers—so that they can live their best life, every day. Without robust funding for all agencies and programs of the public health continuum, we're falling short on the promise to protect Americans and improve health. Short-changing public health and health research programs—or cutting health programs at the expense of others—leaves Americans vulnerable to health threats and does nothing to prevent these problems from arising in the first place.

Despite the importance of these agencies and their programs in protecting Americans' lives, Federal spending for public health and health research represents a small and shrinking share of the budget. In fiscal year 2018 discretionary health spending was only $62 billion, or 1.5 percent of all Federal spending. Of this, more than half supported medical research at the NIH, and the remainder supported all other public health activities—disease prevention & response, health & safety security, workforce development, and access to primary and preventative care.

Funding for public health and health research programs is already well below fiscal year 2010 levels. The return of the austere spending caps at the end of this fiscal year threatens to further shrink public health, health research, and other domestic programs by $55 billion—11 percent across the board—when the Bipartisan Budget Act of 2018 expires. As a founding co-chair of NDD United, the Coalition joins more than 850 organizations in urging Congress and the White House to negotiate a bipartisan budget deal to raise the spending caps as soon as possible. The Coalition for Health Funding supports the Investing for the People Act of 2019 (HR 2021) that lifts the defense and non-defense discretionary spending levels for 2020 and 2021, and we will support other proposals that seek to avoid the coming funding cliff. Previous bipartisan budget agreements have paved the way for modest investments in public health and health research, but they are far short of what is needed to truly improve and protect the health of the population. Lawmakers must build on the success of the previous bipartisan budget agreements to ensure public health and other programs have the resources necessary to carry out their mission.

Raising the caps however, is only the first step in ensuring that public health and health research receive necessary funding. Appropriators must also raise the 302(b) allocation for the Labor-HHS-Education Subcommittee to address its important and long-neglected needs. The bill has never received a proportional funding increase from previous bipartisan budget deals, and as a result has lost almost $16 billion in purchasing power over the last decade; it would require a 302(b) allocation of $194 billion to return to the fiscal year 2010 level in inflation-adjusted dollars. That's why the Coalition for Health Funding partnered with the Campaign to Invest in America's Workforce, Committee for Education Funding, and Coalition on Human Needs in bringing together more than 550 organizations to urge appropriators to raise the subcommittee's allocation in fiscal year 2020 after a decade of stagnation and underinvestment.

There are other challenges on the horizon that complicate the subcommittee's work in fiscal year 2020 that are of great concern to the Coalition for Health Funding. First, the administration's immigration policies continue to take a toll on the health of migrant children and families. Every day there are new headlines about the abuse of children in the government's care, and the trauma sustained by parents separated from their children, who will be at increased risk of mental and physical health complications throughout the rest of their lives. Remedying these failed policies will continue to be a significant cost. HHS has already redirected nearly a billion dollars from the discovery of cures, infectious disease outbreak response, and access to critical and primary care preventative services to support the response. Lawmakers must find a better way to support migrant children and families and address this humanitarian crisis.

Another challenge is that many important mandatory health funding streams are set to expire at the end of fiscal year 2019, including the Community Health Center Fund, National Health Service Corps Fund, and Patient Centered Outcomes Research Trust Fund. The expiration of these funds would leave gaping holes in the discretionary side of the ledger that if not filled by appropriators, would hinder vulnerable Americans' access to care and limit scientific discovery.

Finally, the Coalition is concerned about the challenge posed by the political climate, and the potential for it to cause another government shutdown. After the 35-day shutdown earlier this year—the longest in American history—some Members of Congress have proposed legislation to trigger automatic continuing resolutions (CRs) as a way to prevent future shutdowns. The Coalition is deeply concerned that automatic CRs would harm public health and other domestic programs funded through the annual appropriations process. When the Federal budget process breaks down, and CRs are the norm, it creates dysfunction and disruption across the entire public health continuum. New initiatives, innovations, and hires are put on hold. Procurement cycles lapse. Opportunities are lost and ultimately the American people are hurt. Automatic CRs would only exacerbate this uncertainty and remove the incentives for Congress to complete the appropriations process in a timely manner. For a bill as large and complicated as Labor-HHS—which only narrowly escaped the last shutdown thanks its strategic pairing with the Defense spending bill—we fear automatic CRs would ultimately lead to cuts in health funding, whether the automatic CR would freeze funding at the current year's levels, or require a percentage of cuts.

We hope in your ongoing deliberations on fiscal 2020 and beyond you will recognize the importance of raising the spending caps and consider the costs—both real costs and opportunity costs—of spending cuts, and the value of all public health and health research programs in improving the lives of American families. We look forward to working with the subcommittee in these endeavors, and hope you will turn to the Coalition for Health Funding as a resource in the future.

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

PREPARED STATEMENT OF COLLEGE NOW GREATER CLEVELAND

Dear Chairs DeLauro and Blunt and Ranking Members Cole and Murray,

Thank you for your continued leadership and support of programs and grants that help make postsecondary education a possibility for low-income and middle-income students. The priorities identified in the fiscal year 2020 funding discussion are important to thousands of families for whom postsecondary is a means of economic advancement and opportunity. I write on behalf of College Now Greater Cleveland, a college access organization that serves 29,000 individuals annually in 185 venues across five counties in Northeast Ohio. We respectfully request that Congress appropriate to the U.S. Department of Education funding that would allow for a maximum Pell Grant of $6,095 per student, Supplementary Educational Opportunity Grant funding of $1.028 billion, Federal Work-Study funding of $1.434 billion, TRIO program funding of $1.12 billion, GEAR UP funding of $395 million and 21st Century Learning Grant funding of $1.32 billion. Additionally, we request that the Corporation for National and Community Service receives at a minimum, level funding to support the AmeriCorps program.

College Now helps middle and high school students and their families as well as adult learners navigate the college and career process through one-on-one coaching, financial aid counseling and scholarship and retention services. At its founding in 1967, College Now was the first organization of its kind in the Nation. Since then, it has become the largest college access and success organization in Ohio and remains one of the largest in the country. We know from our work across the region, and research conducted by Cleveland's postsecondary attainment initiative, the Higher Education Compact of Greater Cleveland, that many students are thrown off their paths to and through college because of intractable issues and insurmountable barriers related to college access and affordability. For this reason, we are supportive of the following Federal investments to ensure that more students are able to access and afford postsecondary:

Increase funding for the Pell Grant

Since 1972, the Pell Grant has served as the primary source of Federal support for in-need students. In Ohio, a total of $8 million in Pell Grants is awarded annually to 209,000 students. While we are grateful that Congress continues to prioritize the Pell Grant and even reinstated funding to permit its use for summer coursework, its current allocation is not large enough to match higher education's rising cost. In 1980 the Pell Grant covered 68 percent of college costs, but in 2016–17 it covered only 25 percent of costs. If Pell were to maintain its purchasing power from 40 years ago, the maximum grant would be $15,471; for the 2018–19 school year maximum Pell was $6,095.

To maintain the purchasing power of the Pell Grant, we respectfully request that Congress increase the Pell Grant maximum to $6,753 in fiscal year 2020.

Campus Based Aid—Work Study and SEOG

In addition to increasing Pell, we ask that Congress continue to invest in Federal Work Study (FWS) and the Supplemental Education Opportunity Grant (SEOG). These grants are important parts of the college financing puzzle for low and middle-income family. College Now provides scholarships to over 1,700 Pell-eligible students each year. As part of these students financial aid package they also receive an average of $652 in FWS and $1,149 in SEOG. Even with this support and need-based aid grants, scholarships, institutional aid and Federal loans, these families face an average unmet need of $7,895.

To prevent the college financing gap from growing, College Now respectfully requests that Congress continue its investment of $1.434 billion for Federal Work Study and of $1.028 billion for the Supplemental Education Opportunity Grant.

Federally Funded College Access Programs—TRIO, GEAR UP, and 21st Century CLC's

In addition to facing major affordability challenges, many of the students we serve lack so-called "college knowledge." College knowledge is what the average student with a degree-holding family member have inherently as compared to a student without any exposure to postsecondary success. College Now utilizes funds available through several federally funded college access programs including TRIO Grant programs, GEAR–UP and 21st Century Community Learning Center program to provide students with these critical skills.

College Now is proud to be the recipient of several TRIO Grant programs. Our Upward Bound grants serve students at East Cleveland's Shaw High School and Warrensville Heights High School. These grants allows College Now advisors to provide scholars in these low-income communities with school-based activities that improve academics, promote executive functioning skills and encourage their post-high school aspirations.

College Now's Talent Search grant serves several hundred students within the Cleveland Metropolitan School District. Talent Search helps high schools students from low-income communities, who have potential for success in college, prepare for postsecondary through programming that includes one-on-one advising services, college and career visits, career talks, scholarship clubs and shadowing opportunities. This program provides additional resources and added capacity in schools where such individualized support may otherwise be impossible.

College Now is a proud to implement GEAR UP grants that work to transform the Parma School City School District and the Cleveland Heights/University Heights School District by helping at-risk students prepare for and achieve success in college. College Now staff work at each district to create a college-going culture by providing college campus visits and afterschool activities, and by helping students through the college-going process. College Now has a history of successfully implementing GEAR UP grants. Our participation in a GEAR UP grant, implemented in Elyria from 2006–2011 led to a 36 percent increase in the percentage of students testing at or above grade level in English and a 33 percent increase in the percentage of students testing at or above grade level in mathematics.

After school education programs play an important role in the lives of youth as the time between school ending and when parents return from work can be one with limited supervision. College Now's 21st Century Community Learning Center Grants support an eight-week afterschool program in nine locations across Northeast Ohio to help students improve math and reading skills, ACT scores and increase students' college and career readiness. Upon completion of the program, students receive a $200 stipend and have an opportunity for an internship for which they are also compensated.

College Now respectfully requests that Congress continue its investment in federally funded college access programs at the amounts requested by their communities: $1.12 billion for TRIO, $395 million for GEAR UP, and $1.32 billion for 21st Century Community Learning Centers.

Funding for the Corporation for National & Community Service

College Now is the fiscal agent for a $1.1 million statewide AmeriCorps program that deploys 85 members at 9 host sites across Ohio. College Now also directly manages 31 AmeriCorps College Guides and 10 Coaches in Northeast Ohio. The Guides serve 6th-12th graders with college and career advising and financial aid counseling and serve high school graduates with support to achieve their higher education goals. The Coaches deliver curriculum on career and college pathways to Cleveland Metropolitan School District middle school students and five career academy high schools. Since the program's inception in 2009, 536 College Guides have served 911,200 hours and helped 250,737 Ohio students and adults (primarily first-generation college-goers and students from low-income backgrounds) through the college-going and career readiness process. The AmeriCorps program is critical to providing these important college and career preparation services and giving those who serve valuable community based experiences.

We respectfully echo the request of the Voices for National Service to at a minimum, provide level funding for the CNCS in fiscal year 2020 to allow for the continued support of the AmeriCorps program.

Thank you for this opportunity to provide our funding priorities for the fiscal year 2020. To meet the shifting demand of employers it is critical that more students of all economic backgrounds are able to access and succeed in postsecondary and graduate without excessive debt. Through continued supports—both financial and programmatic—our country can work together to close the attainment gap and promote the health and wealth of its communities. Thank you again for your support of this important goal.

Sincerely.

[This statement was submitted by Lee Friedman, CEO, College Now Greater Cleveland.]

PREPARED STATEMENT OF THE COLLEGE ON PROBLEMS OF DRUG DEPENDENCE

NATIONAL INSTITUTES OF HEALTH

Thank you for the opportunity to submit testimony in support of the National Institute on Drug Abuse. The College on Problems of Drug Dependence (CPDD), a membership organization with over 1000 members, has been in existence since 1929. It is the longest standing group of scholars in the U.S. addressing problems of drug dependence and abuse. CPDD serves as an interface among governmental, industrial and academic communities maintaining liaisons with regulatory and research agencies as well as educational, treatment, and prevention facilities in the drug abuse field. In the fiscal year 2020 Labor-HHS Appropriations bill, we request that the subcommittee provide at least $2.5 billion above the fiscal year 2019 level for the National Institutes of Health (NIH), and within that amount a proportionate increase for the National Institute on Drug Abuse (NIDA) using the Institute's conferenced level of $1,419,844,000 as NIDA's base budget for Fiscal 2020. In addition, within the NIH total, we request at least $500 million for targeted research on opioid misuse and addiction, development of opioid alternatives, pain management, and addiction treatment, of which at least $250 million is allocated to NIDA and included in its base budget for Fiscal 2020. We also respectfully request the inclusion of the following NIDA specific report language.

Opioid Initiative.—The Committee continues to be extremely concerned about the epidemic of prescription opioids, heroin, and illicit synthetic opioid use, addiction and overdose in the U.S. Approximately 174 people die each day in this country from drug overdose (over 100 of those are directly from opioids), making it one of the most common causes of non-disease-related deaths for adolescents and young adults. This crisis has been exacerbated by the availability of illicit fentanyl and its analogs in many communities. The Committee appreciates the important role that research plays in the various Federal initiatives aimed at this crisis. To combat this crisis, the bill includes at least $250,000,000 for research related to preventing and treating opioid misuse and addiction. With additional funding for NIDA targeted at addressing the opioid epidemic, the Institute's opioid specific allocation should be targeted for the following areas: development of safe and effective medications and new formulations and combinations to treat opioid use disorders and to prevent and reverse overdose; conduct demonstration studies to create a comprehensive care model in communities nationwide to prevent opioid misuse, expand treatment capacity, enhance access to overdose reversal medications, and enhance prescriber practice; test interventions in justice system settings to expand the uptake of medication assisted treatment and methods to scale up these interventions for population-based impact; and develop evidence-based strategies to integrate screening and treatment for opioid use disorders in emergency department and primary care settings.

Addressing the Opioid Crisis in Rural Regions.—The Committee encourages NIDA to continue its partnership with the CDC, SAMHSA, and the Appalachian Regional Commission in support of research to help communities develop comprehensive approaches to prevent and treat consequences of opioid injection, including substance use disorders, overdose, HIV, hepatitis B and C virus infections, as well as sexually transmitted diseases. These projects will serve as models for addressing opioid injection epidemics that can be implemented by health systems in similar rural communities in the U.S.

Barriers to Research.—The Committee is concerned that restrictions associated with Schedule I of the Controlled Substance Act effectively limit the amount and type of research that can be conducted on certain Schedule I drugs, especially marijuana or its component chemicals and new synthetic drugs and analogs. At a time when we need as much information as possible about these drugs to find antidotes for their harmful effects, we should be lowering regulatory and other barriers to conducting this research. The Committee directs NIDA to provide a short report on the barriers to research that result from the classification of drugs and compounds as Schedule I substances.

Raising Awareness and Engaging the Medical Community in Drug Abuse and Addiction Prevention and Treatment.—Education is a critical component of any effort to curb drug use and addiction, and it must target every segment of society, including healthcare providers (doctors, nurses, dentists, and pharmacists), patients, and families. Medical professionals must be in the forefront of efforts to curb the opioid crisis. The Committee continues to be pleased with the NIDAMED initiative, targeting physicians-in-training, including medical students and resident physicians in primary care specialties (e.g., internal medicine, family practice, and pediatrics). NIDA should continue its efforts in this space, providing physicians and other medical professionals with the tools and skills needed to incorporate substance use and misuse screening and treatment into their clinical practices.

Marijuana Research.—The Committee is concerned that marijuana public policies in the States (medical marijuana, recreational use, etc.) are being changed without the benefit of scientific research to help guide those decisions. NIDA is encouraged to continue supporting a full range of research on the health effects of marijuana and its components, including research to understand how marijuana policies affect public health.

The HEALthy Brain and Child Development (BCD) Study.—The Committee recognizes and supports the NIH HEALthy Brain and Child Development Study, which will establish a large cohort of pregnant women from regions of the country significantly affected by the opioid crisis and follow them and their children for at least 10 years. This knowledge will be critical to help predict and prevent some of the known impacts of pre- and postnatal exposure to drugs or adverse environments, including risk for future substance use, mental disorders, and other behavioral and developmental problems. The Committee recognizes that the BCD Study is supported in part by the NIH HEAL Initiative?, and encourages other NIH Institutes, such as NICHD, NIMH, NHLBI, NCI, NIAAA, NIMH, NINR, as well as the Office of the Director to support this important study.

Electronic Cigarettes.—The Committee understands that electronic cigarettes (e-cigarettes) and other vaporizing equipment are increasingly popular among adolescents, and requests that NIDA fund research on the use and consequences of these devices. The Committee also supports the Population Assessment of Tobacco and Health (PATH) Study, a collaboration between NIDA and the U.S. Food and Drug Administration (FDA) Center for Tobacco Products to help scientists learn how and why people start using tobacco products, quit using them, and start using them again after they have quit, as well as how different tobacco products affect health outcomes over time.

Drug abuse is costly to Americans; it ruins lives, while tearing at the fabric of our society and taking a financial toll on our resources. Over the past three decades, NIDA-supported research has revolutionized our understanding of addiction as a chronic, often-relapsing brain disease—this new knowledge has helped to correctly emphasize the fact that drug addiction is a serious public health issue that demands strategic solutions.

NIDA supports a comprehensive research portfolio that spans the continuum of basic neuroscience, behavior and genetics research through medications development and applied health services research and epidemiology. While supporting research on the positive effects of evidence-based prevention and treatment approaches, NIDA also recognizes the need to keep pace with emerging problems. We have seen encouraging trends in strategies to address these problems, but areas of continuing significant concern include the recent increase in lethalities due to heroin and synthetic fentanyl, as well as continued abuse of prescription opioids. Our knowledge of how drugs work in the brain, their health consequences, how to treat people already addicted, and what constitutes effective prevention strategies has increased dramatically due to research. However, since the number of individuals who are affected is still rising, we need to continue the work until this disease is both prevented and eliminated from society.

We understand that the fiscal year 2020 budget cycle will involve setting priorities and accepting compromise, however, in the current climate we believe a focus on substance abuse and addiction deserves to be prioritized accordingly. Thank you for your support for the National Institute on Drug Abuse.

PREPARED STATEMENT OF THE CONSORTIUM OF SOCIAL SCIENCE ASSOCIATIONS

On behalf of the Consortium of Social Science Associations (COSSA), I offer this written testimony for inclusion in the official committee record. For fiscal year 2020, COSSA urges the Committee to appropriate $41.6 billion for the National Institutes of Health (NIH); $7.8 billion for the Centers for Disease Control and Prevention (CDC), including $175 million for the National Center for Health Statistics (NCHS); $460 million for the Agency for Healthcare Research and Quality (AHRQ); $655 million for the Bureau of Labor Statistics (BLS); $670 million for the Institute of Education Sciences (IES); and $106.1 million for the Department of Education's International Education and Foreign Language programs.

First, allow me to thank the Committee for its long-standing, bipartisan support for scientific research. Strong, sustained funding for all U.S. science agencies is essential if we are to make progress toward improving the health and economic competitiveness of the Nation. COSSA serves as a united voice for a broad, diverse network of organizations, institutions, communities, and stakeholders who care about a successful and vibrant social science research enterprise. We represent the collective interests of all STEM disciplines engaged in the rigorous study of why and how humans behave as they do as individuals, groups and within institutions, organizations, and society.

NATIONAL INSTITUTES OF HEALTH

COSSA joins the more than 300 stakeholder organizations in support of $41.6 billion for the National Institutes of Health (NIH) in fiscal year 2020. COSSA appreciates the Subcommittee's leadership and its long-standing bipartisan support of NIH, especially during difficult budgetary times. There are, however, ongoing and emerging health challenges confronting the United States and the world, which COSSA believes merits continued investment in the NIH. This funding level would enable real growth over biomedical inflation, an important step to ensuring stability in the U.S. research capacity over the long term.

To be truly transformative, NIH will need to continue to embrace research from a wide range of scientific disciplines, including the social and behavioral sciences. The Office of Behavioral and Social Sciences Research (OBSSR), housed within the Office of the NIH Director, coordinates basic, clinical, and translational research in the behavioral and social sciences in support of the NIH mission, and co-funds highly rated grants in the behavioral and social sciences in partnership with individual institutes and centers. Unfortunately, OBSSR's budget has been held roughly flat for several years despite the sizable increases to the NIH budget. Knowledge about 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. We urge Congress to emphasize support for OBSSR and encourage NIH to increase the Office's budget in fiscal year 2020.

CENTERS FOR DISEASE CONTROL AND PREVENTION

COSSA urges the Subcommittee to appropriate $7.8 billion for the Centers for Disease Control and Prevention (CDC), including $175 million for CDC's National Center for Health Statistics (NCHS). As the country's leading public health and health 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 by informing the CDC's behavioral surveillance systems, public health interventions, and health promotion and communication programs that help protect Americans and people around the world from disease. As the Department of Health and Human Services' principal statistical agency, NCHS produces data on all aspects of our healthcare system, including opioid and prescription drug use, maternal and infant mortality, chronic disease prevalence, healthcare disparities, emergency room use, health insurance coverage, teen pregnancy, and causes of death. As a result of the rising costs of conducting surveys and years of flat or near-flat funding, NCHS has had to focus nearly all of its resources on continuing to produce the high-quality data that communities across the country rely on to understand their health. Additional funding would allow NCHS to respond to rising costs, declining response rates, and an ever-more complex healthcare system and capitalize on opportunities surrounding advances in statistical methodology, big data, and computing to produce better information more quickly and efficiently, while reducing the reporting burden on local data providers.

AGENCY FOR HEALTHCARE RESEARCH AND QUALITY

COSSA urges the Subcommittee to appropriate $460 million for the Agency for Healthcare Research and Quality (AHRQ). This funding level would allow AHRQ to rebuild portfolios terminated as a result of years of past cuts and expand its research and training portfolio to address our Nation's pressing and evolving healthcare challenges. Additionally, with a quarter of the agency's program level budget supported by the Patient-Centered Outcomes Research Trust Fund, a strong investment in the AHRQ appropriation will be essential to sustain the agency's core activities as the Trust Fund undergoes reauthorization this year. AHRQ funds research on improving the quality, safety, efficiency, and effectiveness of America's healthcare system. It is the only agency in the Federal Government with the expertise and explicit mission to fund research on improving healthcare at the provider level (i.e., in hospitals, medical practices, nursing homes, and other medical facilities). Its work is complementary-not duplicative-of other HHS agencies. COSSA urges the Committee to ensure robust support for AHRQ's critical health services research.

BUREAU OF LABOR STATISTICS

COSSA urges the Subcommittee to appropriate $655 million for the Bureau of Labor Statistics (BLS) for its core programs. The Bureau of Labor Statistics produces economic data that are essential for evidence-based decisionmaking by businesses and financial markets, Federal and local officials, and households faced with spending and career choices. The BLS, like every Federal statistical agency, must modernize in order to produce the gold standard data on jobs, wages, skill needs, inflation, productivity and more that our businesses, researchers, and policymakers rely on so heavily. The requested funding level would restore less than half of BLS' loss in budget due to inflation since fiscal year 2009, but would allow BLS to continue to support evidence-based policymaking, smart program evaluation, and confident business investment.

INSTITUTE OF EDUCATION SCIENCES

COSSA requests $670 million for the Institute of Education Sciences (IES) in fiscal year 2020. As the research arm of the Department of Education, IES supports research and data to improve our understanding of education at all levels, from early childhood and elementary and secondary education, through higher education. Research further examines special education, rural education, teacher effectiveness, education technology, student achievement, reading and math interventions, and many other areas. IES-supported research has improved the quality of education research, led to the development of early interventions for improving child outcomes, generated and validated assessment measures for use with children, and led to the establishment of the What Works Clearinghouse for education research, highlighting interventions that work and identifying those that do not. With increasing demand for evidence-based practices in education, adequate funding for IES is essential to support studies that increase knowledge of the factors that influence teaching and learning and apply those findings to improve educational outcomes.

INTERNATIONAL EDUCATION AND FOREIGN LANGUAGE PROGRAMS

The Department of Education's International Education and Foreign Language programs play a major role in developing a steady supply of graduates with deep expertise and high-quality research on foreign languages and cultures, international markets, world regions, and global issues. COSSA urges a total appropriation of $106.1 million ($95.7 million for Title VI and $10.5 million for Fulbright-Hays) for these programs, which would help make up for lost investment and purchasing power after five fiscal years of flat-funding. In addition to broadening opportunities for students in international and foreign language studies, such support would also strengthen the Nation's human resource capabilities in strategic areas of the world that impact our national security and global economic competitiveness.

Thank you for the opportunity to present this testimony on behalf of the social and behavioral science research community.

[This statement was submitted by Wendy Naus, Executive Director, Consortium of Social Science Associations.]

PREPARED STATEMENT OF THE COUNCIL OF ACADEMIC FAMILY MEDICINE

The member organizations of the Council of Academic Family Medicine (CAFM) are pleased to submit testimony on behalf of programs under the jurisdiction of the Health Resources and Services Administration (HRSA) and the Agency for Healthcare Research and Quality (AHRQ). CAFM collectively includes family medicine medical school and residency faculty, community preceptors, residency program directors, medical school department chairs, research scientists, and others involved in family medicine education. We urge the Committee to appropriate at least $59 million for the Primary Care Training and Enhancement program, authorized under Title VII, Section 747 of the Public Health Service Act HRSA. In addition, we recommend the Committee fund the AHRQ at a level of at least $460 million and $5 million dedicated to AHRQ's Center for Primary Care Research.

More than 44,000 primary care physicians will be needed by 2035, and current primary care production rates will be unable to meet the demand, according to the authors of a recent article in Annals of Family Medicine (Petterson, et al Mar/Apr 2015). The primary care training and enhancement programs and AHRQ research enhance our Nation's workforce and health infrastructure, improving primary care services that produce better health outcomes and reduce healthcare costs.

PRIMARY CARE TRAINING AND ENHANCEMENT—TITLE VII

The Primary Care Training and Enhancement Program (Title VII, Section 747 of the Public Health Service Act) has a long history of funding training of primary care physicians. As experimentation with new or different models of care continues, departments of family medicine and family medicine residency programs will rely further on Title VII, Section 747, grants to help develop curricula and research training methods for transforming practice delivery. Future training needs include: training in new clinical environments that include integrated care with other health professionals (e.g. behavioral health, care coordination, nursing, oral health); development and implementation of curricula to give trainees the skills necessary to build and work in inter-professional teams that include diverse professions; and development and implementation of curricula to develop leaders and teachers in practice transformation. Moreover, new competencies are required for our developing health system.

The Advisory Committee on Training in Primary Care Medicine and Dentistry December 2014 report states that "[r]esources currently available through Title VII, Part C, sections 747 and 748 have decreased significantly over the past 10 years, and are currently inadequate to support the [needed] system changes."[1] In order to address some of these challenges, the Advisory Committee recommended that Congress increase funding levels for training under the primary care training health professions program to meet the pent-up demand caused by reduced and stagnant funding levels. We are pleased that Congress increased spending for primary care training and enhancement in fiscal year 2018 and continued such funding in fiscal year 2019. We are hopeful that the Committee will realize the need for continued and increased funding to allow for a more extensive support across the Nation for schools and residency programs whose trainees are on the forefront of addressing challenges in primary care.

Primary care health professions training grants under Title VII are vital to the continued development of a workforce designed to care for the most vulnerable populations and meet the needs of the 21st century. We urge your continued down payment for this program and an increase in funding levels to $59 million in fiscal year 2020 to allow for a robust competitive funding cycle.

This funding level will help continue important Title VII programs such as The Preparing Primary Care Trainees to Transform Health Care Systems program at the Kirksville College of Osteopathic Medicine in Missouri. This program uses grant funding to create enhanced primary care didactics, contextual clinical learning activities and assessments and leadership tracks to prepare students and facility for practice in changing and diverse health systems.

AGENCY FOR HEALTH CARE RESEARCH AND QUALITY

Primary care clinical research is a core function of AHRQ. Primary care research includes: translating science into patient care, better organizing healthcare to meet patient and population needs, evaluating innovations to provide the best healthcare to patients, and engaging patients, communities, and practices to improve health. AHRQ has proved to be uniquely positioned to support best practice primary care research and to help disseminate the research nationwide. However, reduced levels of AHRQ funding in the past have exacerbated disparities in funding primary care research. Important primary care research initiatives have been unfunded in recent years such as research for patients with Multiple Chronic Conditions (MCC) and the statutorily authorized Center for Primary Care Research.

With funding increased for fiscal year 2019 to $338 million, AHRQ is in a unique position to further primary care clinical research as well as the implementation science to identify how to deploy new knowledge into the hands of primary care providers and systems in communities. However more funding is needed to accomplish these goals. For this reason, we are supporting additional overall funding increases for fiscal year 2020 as well as specific funding for the Center for Primary Care Research of $5 million to help coordinate and direct primary care research funding at AHRQ. We hope additional funding will continue and expand the following goals: (1) development of clinical primary care research and researchers (2) real world application of evidence, (3) the process of practice and health system transformation, (4) how high functioning primary care systems and practices should look, (5) how primary care practices serving rural and other underserved populations adapt and

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[1] http://www.hrsa.gov/advisorycommittees/bhpradvisory/actpcmd/Reports/eleventhreport.pdf.

survive, and (6) how health extension systems serve as connectors of research institutions with practices and communities.

AHRQ research is used by practices and universities across the Nation. This funding level will help continue important programs such as the one at University of Washington. The University of Washington used funding from AHRQ to develop a system to incorporate Patient-Reported Outcomes (PRO) into clinical assessments and decisionmaking leading to improved patient-provider communication, patient satisfaction, and treatment monitoring. The project employs systems engineering methods, human-centered design, and mixed-research methods to develop more effective integration of PRO data into patient care activities through health information technology.

Highlighting the success of AHRQ's patient safety initiatives, a 2014[2] report showed hospital care to be much safer in 2013 compared to 2010. The report noted a decline of 17 percent in hospital-acquired conditions, in harm to 1.3 million individuals, as well as 50,000 lives saved, and $12 billion in reduced health spending during that period. AHRQ supports this research that is essential to create a robust system for our Nation that delivers quality of care while reducing the rising cost of care.

The Administration's fiscal year 2020 budget again proposed eliminating AHRQ and moving some functions into the National Institutes of Health (NIH). CAFM supports an alternative approach of a study described in report language in the fiscal year 2018 spending bill. It's critical that AHRQ retains its current unique purpose supporting primary care research.

In conclusion, we support increased funding for AHRQ at the level of $460 million for fiscal year 2020 which would support important primary care and health services research efforts. We also support $5 million in new funding for the Center for Primary Care Research.

CAFM looks forward to working with the Subcommittee to protect HRSA primary care programs and AHRQ—both entities enhance our Nation's primary care workforce and infrastructure.

[This statement was submitted by Karen Mitchell, MD, Chair, Council of Academic Family Medicine.]

PREPARED STATEMENT OF THE COUNCIL OF CHIEF STATE SCHOOL OFFICERS

Dear Chairs Shelby and Blunt and Ranking Members Leahy and Murray:

On behalf of chief State school officers across the country, I am writing to convey States' priorities for K–12 education in the fiscal year 2020 appropriations cycle. The Council of Chief State School Officers (CCSSO) is a nonpartisan, nationwide, nonprofit organization of public officials who head departments of elementary and secondary education in the States, the District of Columbia, the Department of Defense Education Activity, and five U.S. extra-State jurisdictions. CCSSO provides leadership, advocacy, and technical assistance on major educational issues.

State education leaders are committed to creating a more equitable education system for every child. In 2017, CCSSO released Leading for Equity, a set of ten actions States are committed to taking to improve educational equity in their States. Across these commitments, States demonstrate how they can better align Federal, State, and local resources to advance equity for all students. Funding is a key component, though not the only component, and State chiefs see the Federal funding they receive as a significant resource to improve educational outcomes. For these reasons, we were pleased when Congress passed a bipartisan fiscal year 2019 funding bill. This legislation provided critical funding increases for major K–12 education programs, such as ESEA Title I and the Individuals with Disabilities Act.

As States implement the Every Student Succeeds Act (ESSA), which reauthorized the Elementary and Secondary Education Act (ESEA) in 2015, Federal funding is as critical as ever to ensure States can implement State plans aligned with ESSA with fidelity. This is also true as States embark on implementing the recently reauthorized Carl D. Perkins Career and Technical Education Act (CTE).

As stewards of limited resources, State chiefs recognize that every taxpayer dollar is precious and must be administered efficiently and effectively to better meet the needs of all students. As States move to implement ESSA, CTE and other Federal programs, they are also working to improve State and local stewardship over limited Federal funds to ensure maximum impact to improve student achievement, particu-

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[2] Publication # 15–0011–EF.

larly for disadvantaged or traditionally underserved students, as well as children with disabilities.

CCSSO and our members look forward to working with Congress to ensure that fiscal year 2020 appropriations provide the resources needed to improve outcomes for all children in every State, and emphasize the following K–12 funding priorities:

ELEMENTARY AND SECONDARY EDUCATION ACT

Increase funding for ESEA Title I, Part A

Title I, Part A of ESEA is at the core of the Federal-State partnership in K–12 education. As reauthorized by ESSA, Title I–A provides increased flexibility for States, while also calling on States to develop and implement new accountability and school improvement systems to support academic excellence and reduce achievement gaps. State chiefs have committed to creating a more equitable education system for all students, and this is the continued goal and purpose of Title I Federal funding. During school year 2020–2021, when States and school districts will be receiving fiscal year 2020 funding, they will be working to increase achievement and improve student outcomes in schools that have been identified for support and improvement through new State accountability systems. It is essential that States and their districts have the resources needed to bring those efforts to fruition. To support State leaders in meeting the educational needs of all students, we urge Congress to fund this critical program at the authorized level of $16,182,345,000 in fiscal year 2020.

Provide Authorized Funding for ESEA State Assessment Grants

ESSA continues to require that States administer annual assessments in specified grades in reading or language arts, in mathematics, and in science. These assessments provide much of the framework for States' systems of school accountability; that is, they provide the information that States use to determine which schools are succeeding in educating all their students to high standards. Yet high-quality assessment can be resource-intensive, and States continue to rely on Federal assistance in meeting this important requirement of the reauthorized statute.

Authorized under Title I of ESEA, State Assessment Grants support State efforts to develop and implement high-quality assessments to measure the academic achievement of all students. Under ESSA, States and school districts may also use these funds to audit assessment systems in order to reduce unnecessary or duplicative assessments. According to the Brookings Institution, States spend an estimated $1.7 billion on assessments each year, yet the Federal program pays for $378 million of that cost. State chiefs ask Congress to maintain State Assessment Grants at the full authorized level of $378,000,000 to ensure that students are appropriately assessed and effective targeted instructional supports to improve academic achievement are identified.

Provide Authorized Funding for ESEA Title II, Part A, to Support Effective Instruction

Under ESSA, every student is required to have a highly effective teacher. No longer can poor or minority students be disproportionately served by ineffective or out-of-field teachers. Title II, Part A funding is critical to support States and local districts in this important effort.

Communities across the country use flexible Title II–A funds to develop the workforce they need to best serve their least advantaged students. New Mexico, for example, uses this funding to provide professional development and mentorship programs for teachers and principals in the State's lowest-performing schools. As a result, these schools have improved proficiency rates for their students in English Language Arts by 4.5 times the rate of statewide growth and 2.7 times the statewide growth rate in mathematics. Nevada plans to use Title II–A funds to modernize its licensure requirements to incorporate meaningful professional growth and educator effectiveness and make improvements in the statewide evaluation system to ensure reliability, validity, fairness, consistency, and objectivity. Massachusetts will use this funding to review its school districts' use of Federal funds and make sure that professional development supports more effective educators, particularly those who serve students with disabilities, low-income students, and students of color.

These examples of effective uses of Title II–A funding are just a sample of the efforts States are undertaking to support high-quality teaching and learning. Chiefs urge Congress to continue to support these Federal-State partnerships by funding the program at the authorized level of $2,295,830,000 to increase teacher effectiveness and support the use of proven strategies to improve learning outcomes.

Preserve Funding for ESEA Title III

English learners (ELs) are a growing population group across States, and in recent years their enrollment has increased particularly in States where schools have limited experience in serving them. Enabling ELs to achieve English language proficiency and achieve to high standards in the regular, English-speaking classroom, is one of the key responsibilities given to States by ESSA. Under the reauthorized statute, States must set goals for ELs' attainment of English proficiency and incorporate a measure of progress toward that goal in their systems of school accountability. For this reason, school year 2019–2020 will be a critical time during which States test all ELs for proficiency, implement systems for improving educational programs for the EL population, and provide services and supports to schools that are not making sufficient progress in that area.

Title III of ESEA funds State and local programs in English language acquisition for EL and immigrant students. To ensure the success of States' efforts to improve outcomes for this high-need and growing population, we recommend that the Congress fund Title III at the authorized level of $884,960,000.

Adequately Fund ESEA Title IV, Part A, the Student Support and Academic Enrichment Grant

Title IV, Part A, the Student Support and Academic Enrichment Grant program, provides Federal support for programs that support a well-rounded education, safe and healthy students, and education technology. Newly authorized by ESSA, this program received its first appropriation of $400 million in fiscal year 2017, followed by an increase to $1.1 billion and $1.2 billion in fiscal year 2018 and fiscal year 2019 respectively.

In addition to using these funds to provide students with a well-rounded education, States have committed to ensuring student safety by focusing on school culture, climate, and social-emotional development. To keep students safe, State leaders recognize this work takes multiple approaches such as securing school facilities and a strong focus on how to deepen and strengthen communities. Title IV is particularly critical as States and local communities seek to improve school safety; it remains critically important that we support State and local leaders in providing safe, supportive school environments for all students, and we urge Congress to fund Title IV, Part A at the authorized level of $1.6 billion.

Adequately Fund ESEA Title IV, Part B, 21st Century Community Learning Centers

One way in which State chiefs have worked to strengthen students' relationships with their communities is through afterschool programs. Chiefs urge Congress to adequately fund 21st Century Community Learning Centers so students have the supports they need outside of the classroom to ensure success in school and in life. This program provides students with activities to enhance their academic, social, and overall development during their out-of-school time. Approximately 1.9 million students benefit from these programs in schools, libraries, and communities across the country. Data show that students who participate in these programs miss fewer days of school, have fewer out-of-school suspensions, increase their chances of graduating, and are more likely to continue their education after high school. Congress should fund this program at no less than $1,211,673,000, the amount provided in fiscal year 2019.

Support Statewide Longitudinal Data Systems

Statewide Longitudinal Data Systems (SLDS) funding has helped State education agencies provide State leaders, district administrators, educators, and the education community with high-quality data on student achievement and other student outcomes and on school performance. States use these funds to create more efficient and effective data systems, including new ESSA requirements such as reporting on homeless, foster, and military-connected youth, and per-pupil expenditure at the school level. For example, one State used SLDS grants to streamline the data collection process that school districts must navigate annually, thereby reducing administrative burden. Through automation this State has saved over $500,000 annually on a single data collection requirement. These savings are driven into more important services locally, such as teaching and learning activities. Meanwhile, another State used an SLDS grant to develop and implement a custom technology tool to provide educators with near real-time data to help inform instruction. Chiefs urge Congress to build on these and similar successes by funding this program at least at the fiscal year 2019 level of $32,281,000.

CARL D. PERKINS CAREER AND TECHNICAL EDUCATION ACT

Adequately Fund the Carl D. Perkins Career and Technical Education Act

States are leading efforts to ensure that students graduating from high school are prepared to enroll in postsecondary education or enter the workforce with industry-recognized certifications or credentials that can lead them to a well-paying career. In partnership with JPMorgan Chase, Advance CTE and Education Strategy Group, CCSSO is leading the New Skills for Youth Initiative and working with States to increase the number of students who graduate prepared to compete in an evolving job market. To support State leaders as they implement the recently passed Perkins Act and produce graduates who are both college- and career-ready and ensure all students have access to pathways that prepare them for the workplace of tomorrow, chiefs urge Congress to appropriate at least $1,262,598,000 for the Perkins Career and Technical Education State Grants program, consistent the President's proposed budget.

INDIVIDUALS WITH DISABILITIES EDUCATION ACT

Invest in the Individuals with Disabilities Education Act

IDEA (Individuals with Disabilities Education Act), Part B supports State and local programs for students with special needs. IDEA funding can also be used to provide more comprehensive supports that benefit all students, such as implementing a universal design for learning curriculum, planning and implementing new learning environments to support all learners in an inclusive setting, or purchasing curriculum-based screening and progress monitoring instruments. While ideally the Federal Government would meet the statutory objective of funding 40 percent of the additional costs of educating students with disabilities, we understand that even with higher spending caps this is a challenging goal under current circumstances. In the fiscal year 2019 funding bill, Congress appropriated $12.3 billion for IDEA, a significant increase over previous years, but still far short of the Federal commitment. Therefore, chiefs ask Congress to increase the Federal Government's share of the excess costs of special education services to about 15 percent, or $12,850,000,000 for IDEA to strengthen services for our students with disabilities.

Thank you for considering the appropriations priorities of chief State school officers and the students they serve. As States move to advance equity in the public education system and implement ESSA and other key Federal and State programs, it is imperative that the Federal Government remain a key partner in supporting the work underway in States to provide the necessary resources to meet the needs of all students, particularly students who have been traditionally underserved by our education system.

Sincerely.

[This statement was submitted by Carissa Moffat Miller, Executive Director, Council of Chief State School Officers.]

PREPARED STATEMENT OF THE COUNCIL OF STATE AND TERRITORIAL EPIDEMIOLOGISTS

I am Janet Hamilton, Director of Science and Policy at the Council of State and Territorial Epidemiologists (CSTE). CSTE is organization of 56 member States and territories representing applied public health epidemiology and serves as the professional home for 2,000 applied public health epidemiologists nationwide. As the subcommittee works on the fiscal year 2020 Labor, Health and Human Services, Education and Related Agencies appropriations bill, we respectfully request that you appropriate $100 million in fiscal year 2020 to the Centers for Disease Control and Prevention's (CDC) Public Health Scientific Services for a new, cross-cutting initiative that will transform public health and save lives.

This initial down payment, as part of a $1 billion investment over the next decade, would allow CDC, State, local, tribal, and territorial health departments to move from sluggish, manual, paper-based data collection to seamless, automated, interoperable, and secure data systems that yield critical health information in real-time. This funding would also support efforts to modernize the public health workforce by training, recruiting (e.g., student loan repayment and fellowships), and retaining skilled data scientists. Data systems require adept staff to use them, maintain them, interpret the data, and develop and deploy actionable public health interventions to save lives.

Whether it's Ebola, dengue, lead, wildfires, or tornados, public health threats are persistent and consistently evolving here at home and overseas. Effective prevention and efficient, timely, responses rely on an interactive network of governmental public health agencies at the Federal, State, local, tribal, and territorial levels working with healthcare providers and the public. Each day, this cooperative network saves lives by detecting and responding to health threats, like E. coli contaminated lettuce, measles, influenza, opioid overdoses, Zika, and more.

Unfortunately, the Nation's public health data systems are antiquated, rely on obsolete information sharing methods, and are in dire need of security upgrades. Lack of interoperability, reporting consistency, and data standards leads to errors in quality, completeness, timeliness, and communication. Sluggish, manual processes-paper records, phone calls, spreadsheets, and faxes requiring manual data entry-still in widespread use have important consequences, most notably delayed detection and response to public health treats of all types: chronic, emerging, and urgent. Rapid advances in data science and evolving cybersecurity threats demand public health professionals with new skills to protect, defend privacy, and securely integrate health data.

In my experience on the front lines of public health emergency detection, prevention, and response as a Florida epidemiologist during the 2009 H1N1 influenza pandemic, locally acquired dengue outbreak, Deepwater Horizon Gulf oil spill, multistate fungal meningitis outbreak, Zika, 11 major hurricanes, the opioid epidemic, and now in my role representing State and local epidemiologists nationwide, I have seen first-hand and heard from colleagues about the challenges and frustrations with the current data infrastructure. For example:

—My colleague in Pennsylvania, working in concert with CDC and the Agency for Toxic Substances and Disease Registry (ATSDR), is responding to a manufacturing plant "bad actor" that has released lead into the air. The community understandably wants answers about their health: What are our blood levels? How many people and children have been tested? How do they compare to other communities? Does my child need to be tested? Unfortunately, those questions can't be answered with today's data, because while healthcare facilities have data stored in electronic medical records, data are sent on paper to the health department and the stacks take time to enter and process. Included as an appendix are examples of the millions of hand-written, paper lead lab reports that I received while in Florida.

—After the hurricanes in 2017 and 2018, colleagues in North Carolina and Puerto Rico were asked by policymakers, the media, and the public about the number of hurricane related deaths—where did they occur and what populations were most vulnerable? What immediate steps could be taken to prevent more deaths based on the data? Unfortunately, because of the lag in paper-based data systems, neither the North Carolina officials nor the Puerto Rico officials could give fast, high-quality answers the public wanted, needed, and expected.

—More recently, a colleague shared a story from the frontlines of the E. coli lettuce outbreak, where public health professionals took pictures of their computer screens to share via text messages images of lab reports from implicated food samples identifying the linkage to human illness. Why? Because key electronic data systems storing epidemiologic and laboratory data had no way to seamlessly share the information and speed the response.

These modes of data sharing are slow and cumbersome. They are also vulnerable. With sophisticated cybersecurity threats, it is critical that public health systems are equipped to prevent and respond to cyberattacks. Healthcare providers are required to report diseases and conditions to public health departments. These health records contain sensitive personal information—required to be reported and protected by State laws—and they demand significant care in handling to protect the privacy and safety of patients, particularly since such systems are frequently the target of hackers.

The Nation's public health infrastructure is so fragmented and antiquated that healthcare providers who already have the data stored and collected in electronic health records cannot rapidly share these health data because public health departments cannot receive them electronically. This environment leads to an increased burden on providers to report—or delays and failures to report—and inefficiency and frustration on the part of both care providers and public health professionals. It leads to lost time, lost opportunities, and lost lives. For in any outbreak—where E. coli contaminated lettuce or Listeria contaminated ice cream must be recalled, where measles patients need to be isolated to prevent others from becoming infected, where influenza threatens the lives of pregnant mothers—time matters. Data matters.

Public health professionals, providers, policymakers, and the public will all agree that we need more, better, faster, and secure data to protect health. To date, in our quest for better data, we have taken a piecemeal, fragmented approach. When a new disease emerges, such as Zika, Congress has funded standalone data systems at CDC to support the response. But this funding approach is inconsistent and doesn't support an invested, sustainable approach in detection and prevention before an event, instead waiting and allowing multiple people to become ill because the data is moving slower than the disease. For example, during the Zika response, emergency funds came to Florida months after the initial cases were identified. While Congress's support and funding during emergencies is critical to support a response, a well-planned, long-term, optimal data collection and data system management is not 'one and done'.

CSTE and our partners in this effort—the Association of Public Health Laboratories (APHL), the National Association for Public Health Statistics and Information System (NAPHSIS), and the Healthcare Information and Management Systems Society (HIMSS)—together with more than 80 other institutions representing patients and consumers, public health professionals, healthcare providers, and health systems believe the time has come to step up and take a coordinated, comprehensive, strategic approach to building a public health data super highway of the 21st Century. This interstate system of systems will seamlessly and securely collect sensitive data about diseases and conditions from healthcare providers and report it automatically to public health departments, link it to other key data—including birth and death records—and where required to be reported nationally, share that data seamlessly and securely with CDC. Once built, you can put any "car" or data you want on this interstate, whether a "car" for opioid, Zika, or gun violence.

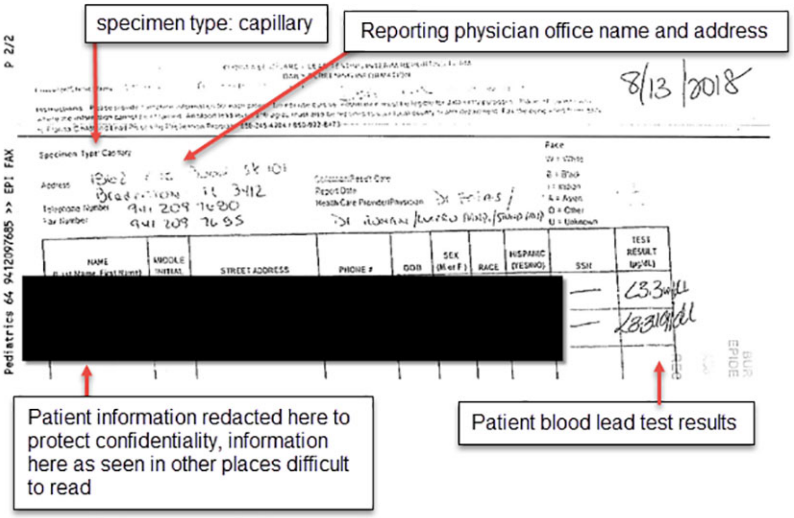
And while our proposed approach to funding this IT modernization is new, what we're proposing isn't. The data systems that feed this public health information superhighway already exist, have demonstrated value, and are used to varying degrees in all State and local public health departments. What we need is to bring all jurisdictions online with all of these systems, and to modernize receiving, sharing, and connecting data that exists in silos. In addition, CDC needs its own secure data platform to receive data electronically from the States via the National Notifiable Disease Surveillance System.

CSTE hopes in your ongoing deliberations on fiscal year 2020 and beyond you will consider the need for a modernized, electronic, interoperable public health data system and a new generation of skilled public health data scientists. Data and workforce are the lifeblood of public health action. We recognize the need for lawmakers to raise discretionary the caps to avoid devastating spending cuts to public health and all domestic programs. We also recognize this effort must be funded with new money, rather than cut already underfunded public health programs. A robust, sustained commitment to transform today's public health data system will ultimately improve Americans' health. We look forward to working with the subcommittee in these endeavors and hope you will turn to the CSTE as a resource in the future.

ADDENDUM

Example.—Lead test results received by the Florida Department of Health as submitted by a private provider to fulfill required lead test result reporting, August 2018, January 2019.

Patient information, test results, and reporting provider information difficult to read and creates delays in identifying the patient as well as recording the data in the health departments data system necessary to identify any community increases in blood lead, respond and implement control measures. While these examples are lead data, data across all diseases and conditions are regularly submitted and received via paper by private providers to public health.


specimen type: capillary

Reporting physician office name and address

P 2/2

Pediatrics 64 9412097685 >> EPI FAX

8/13/2018

Specimen Type: Capillary

Address [illegible]
Bradenton FL 3412
Telephone Number 941 209 7680
Fax Number 941 209 7695

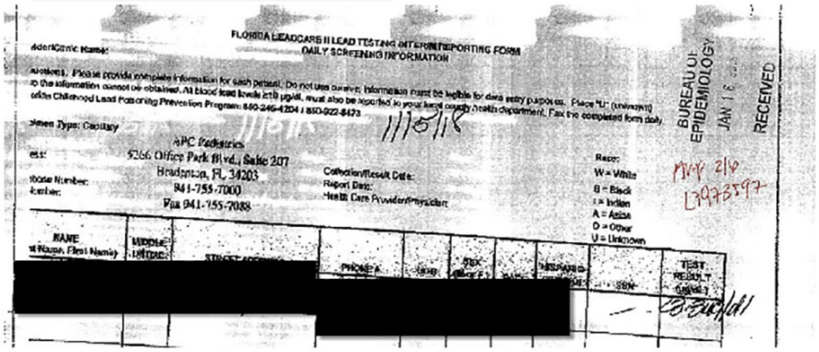
Collection/Result Date
Report Date
Health Care Provider/Physician

Race
W = White
B = Black
I = Indian
A = Asian
O = Other
U = Unknown

NAME (Last Name, First Name)	MIDDLE INITIAL	STREET ADDRESS	PHONE #	DOB	SEX (M or F)	RACE	HISPANIC (YES/NO)	SSN	TEST RESULT (μg/dL)
[redacted]								—	<3.3ug/dl
								—	<3.3ug/dl

Patient information redacted here to protect confidentiality, information here as seen in other places difficult to read

Patient blood lead test results


FLORIDA LEADCARE II LEAD TESTING INTERIM REPORTING FORM
DAILY SCREENING INFORMATION

der/Clinic Name:

uctions: Please provide complete information for each patient. Do not use cursive; information must be legible for data entry purposes. Place "U" (unknown) p the information cannot be obtained. All blood lead levels ≥10 μg/dL must also be reported to your local county health department. Fax the completed form daily the Childhood Lead Poisoning Prevention Program: 850-245-4204 / 850-922-8473

imen Type: Capillary

1/15/18

APC Pediatrics
ess: 5266 Office Park Blvd., Suite 207
Bradenton, FL 34203
phone Number: 941-755-7000
umber: Fax 941-755-7088

Collection/Result Date:
Report Date:
Health Care Provider/Physician:

Race:
W = White
B = Black
I = Indian
A = Asian
O = Other
U = Unknown

BUREAU OF EPIDEMIOLOGY
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MMP 2/6
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NAME (st Name, First Name)	MIDDLE INITIAL	STREET ADDRESS	PHONE #	DOB	SEX	RACE	HISPANIC	SSN	TEST RESULT (μg/dL)
[redacted]			[redacted]					—	<3.3ug/dl

[This statement was submitted by Janet Hamilton, Director, Science and Policy, Council of State and Territorial Epidemiologists.]

Prepared Statement of Council on Social Work Education

On behalf of the Council on Social Work Education (CSWE), I am pleased to offer this written testimony to the Senate Appropriations Subcommittee on Labor, Health and Human Services, Education, and Related Agencies. CSWE is a nonprofit national association representing more than 2,500 individual members and more than 800 baccalaureate and master's programs of professional social work education. CSWE asks the Committee to consider the following funding requests:

Agency	Account	Program	Funding Requested
HHS	HRSA	Behavioral Health Workforce Education and Training Grant Program.	$90 million
HHS	HRSA	Scholarships for Disadvantaged Students	$53.47 million
DHHS	HRSA	Geriatrics Programs	$51 million
HHS	SAMHSA	Minority Fellowship Program	$15.169 million
HHS	HRSA	New authorized demonstration to strengthen mental and substance use disorders workforce.	$10 million
HHS	HRSA	New Loan Repayment Program for Substance Use Disorder Treatment Workforce.	$25 million
HHS	HRSA	Mental and Behavioral Health Programs	$36.916 million

Agency	Account	Program	Funding Requested
ED	N/A	Pell Grant	$6,345 for the maximum Pell Grant
ED	N/A	GAANN	$48 million
ED	N/A	Public Service Loan Forgiveness (PSLF)	Increase support for the PSLF program
HHS	NIH	Overall Funding for NIH	At least $41.6 billion

HRSA TITLE VII HEALTH PROFESSIONS PROGRAMS

CSWE urges the Committee to provide $455.47 million in fiscal year 2020 for the health professions education programs authorized under Title VII of the Public Health Service Act and administered through the Health Resources and Services Administration (HRSA). These programs support the development of a healthcare workforce, including in underserved areas and populations. Through stipends, as well as grants and contracts to academic institutions and nonprofit organizations, Title VII programs develop a workforce that reflects the population it serves, while providing high-quality care and improving access to care for all populations, including underserved communities. Components of these programs include interdisciplinary training, community-based training, training in public health and preventive medicine, and other initiatives. Schools and programs of and social work students are eligible for Title VII health professions programs. Within the Title VII program, CSWE specifically urges the Committee to provide:

—$90 million for HRSA's Behavioral Health Workforce Education and Training (BHWET) program. CSWE appreciates the increased investments in the fiscal year 2019 Labor-H enacted appropriations for the BHWET program. BHWET supports the recruitment and education of behavioral healthcare providers, which is critical as the Nation continues to combat the opioid crisis and substance use disorders. According to a June 2018 HRSA study, out of the 4,618 behavioral health professionals participating in the BHWET program, 3,523 included new social workers.[1] In 2018, a new 4-year competition awarded social work programs to help develop and expand the behavioral health workforce serving populations across the lifespan, including in rural and medically underserved areas. We hope you will support $90 million for BHWET in fiscal year 2020.

—At least $53.47 million for Scholarships for Disadvantaged Students (SDS), as included in the House Committee's bill. This program helps increase minority representation in the health professions. This is essential for the development of a pipeline of health professionals to meet health needs of underserved individuals and communities. Furthermore, this program provides much needed opportunities for students from disadvantaged backgrounds.

—$10 million for a demonstration program to strengthen the mental and substance use disorders workforce. CSWE is pleased the 21st Century Cures Act passed Congress with strong bipartisan support. Included in the mental health provisions of this bill, in Section 9022, is a new demonstration program to strengthen the mental and substance use disorders workforce. Specifically, this provision would support training for health professions, including social workers, to provide mental and substance use disorders services in underserved community-based settings that integrate primary care and mental and substance use disorders services. Furthermore, we urge you to specifically State that social workers are eligible to participate in this program, as outlined in law.

—$36.916 million for Mental and Behavioral Health programs at HRSA. CSWE was pleased to see new investments in mental and behavioral health programs at HRSA to support, recruit, and train professionals and faculty in the fields of social work, psychology, psychiatry, marriage and family therapy, substance abuse prevention and treatment, and other areas of mental and behavioral health. CSWE urges the Committee to ensure that funding from this account supports social work either for education and training.

—$25 million for the Loan Repayment Program for Substance Use Disorder Treatment Workforce. CSWE was pleased to see programs to address shortages in the substance use disorder workforce included in the SUPPORT Act. As one of the largest providers of professional substance use and mental health services in the U.S., social workers are in a unique position to impact the lives of millions of Americans battling addiction. Federal support for education and train-

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[1] Closing Behavioral Health Workforce Gaps: A HRSA Program Expanding Direct Mental Health Service Access in Underserved Areas; American Journal of Preventive Medicine.

ing programs is critical to ensuring our Nation has the proper supply of health professionals to meet growing demands. We hope you will support $25 million for this important program in fiscal year 2020.

SAMHSA MINORITY FELLOWSHIP PROGRAM

CSWE urges the Committee to appropriate at least a $2 million increase for the Minority Fellowship Program (MFP) in fiscal year 2020, as provided in the House appropriations bill reported out of Committee. For almost 45 years, the MFP has been increasing the number of professionals prepared to reduce the effects of substance abuse and mental illness on America's communities by increasing the number of individuals trained to work with underrepresented and underserved racial/ethnic minority persons with or at risk for mental health and/or substance abuse disorders. CSWE appreciates increased investments in the MFP in fiscal year 2019 focused on addiction medicine to address the opioid crisis. CSWE urges Congress to provide at least $15.169 million for MFP in fiscal year 2020 and ensure that increased funding for the program supports all current grantees.

DEPARTMENT OF EDUCATION (ED): STUDENT AID PROGRAMS

CSWE supports full funding to bring the maximum individual Pell Grant to $6,345 in fiscal year 2020. Pell Grants are foundational in providing access and affordability to ensure that all students, regardless of economic situations, can pursue higher education. CSWE also urges Congress to consider increasing the amount of mandatory funding that goes to Pell.

The Graduate Assistance in Areas of National Need (GAANN) program provides graduate traineeships in critical fields of study. We encourage ED to include social work in the GAANN program to enhance graduate education opportunities in social work, which will foster a sustainable health professions workforce. CSWE urges Congress to support the funding level of $48 million in fiscal year 2020 for the GAANN program. The request is the inflation adjusted number from the program's fiscal year 2010 level of $41 million.

CSWE appreciates the support Congress provided for the Public Service Loan Forgiveness (PSFL) program in fiscal year 2019. CSWE urges Congress to continue to protect this program and its implementation by the Department of Education.

NATIONAL INSTITUTES OF HEALTH: SUPPORT FOR RESEARCH

For fiscal year 2020, CSWE supports $41.6 billion for the National Institutes of Health (NIH). CSWE thanks Congress for its support of sustained funding increases for NIH. To build on the advances in research, CSWE hopes you will support continued investments in biomedical and health-related research that incorporates the social and behavioral science research necessary to better understand and address the needs of high-risk populations including children, minority, and geriatric populations.

Thank you for the opportunity to express these views. Please do not hesitate to call on the Council on Social Work Education should you have any questions or require additional information.

[This statement was submitted by Dr. Darla Spence Coffey, President, Council on Social Work Education.]

PREPARED STATEMENT OF THE CREUTZFELDT-JAKOB DISEASE FOUNDATION

Chairman Blunt, Ranking Member Murray, and Members of the Subcommittee:

On behalf of the Creutzfeldt-Jakob Disease (CJD) Foundation, we appreciate the opportunity to submit this testimony in strong support for funding of the crucial prion disease work being undertaken by the Centers for Disease Control in partnership with public health agencies around the country and the National Prion Disease Pathology Surveillance Center (NPDPSC).

The CJD Foundation is a patient advocacy organization for those affected by Prion Diseases. We work closely with families, physicians, researchers, and public health officials to ensure that all possible efforts are taken to prevent transmissible forms of the disease. Given the importance of prion surveillance to public health, we are extremely disappointed to see that the President's budget proposal would eliminate the $6 million appropriation to the Centers for Disease Control and Prevention (CDC) for prion disease. Indeed, the growing threat posed by Chronic Wasting Disease (CWD) has placed additional strains on the CDC's limited prion disease resources and warrants a budgetary increase. As such, we are requesting that the budget for prion disease surveillance be restored and increased to $8 million to appropriately deal with emerging prion disease threats occurring within our borders.

OVERVIEW

Creutzfeldt-Jakob Disease (CJD), is a rare,100 percent fatal, degenerative brain disease that causes rapidly progressive dementia, memory loss, visual disturbances, motor skill impairments, and involuntary movements. Patients most often progress from initial symptoms to death in less than a year. CJD, caused by "prion" proteins, is transmissible and presently has no treatment or cure. Approximately 1 in 6,000 individuals die from this disease, however, the number of unreported and undiagnosed cases remains unclear.

CJD/Prion Disease surveillance receives modest support through the Centers for Disease Control and Prevention (CDC), Emerging and Zoonotic Diseases. The Administration's budget has proposed eliminating Prion Disease Surveillance in fiscal year 2020. We need your support to strengthen and continue the coordination of prion surveillance and to protect the safety of the American public and the Nation's food supply.

VARIANT CJD AND BOVINE SPONGIFORM ENCEPHALOPATHY

One form of Prion Disease in humans, variant CJD (vCJD), is known to be caused by ingesting beef contaminated with Bovine Spongiform Encephalopathy (BSE), more commonly known as "mad cow" disease. The most recent U.S. case of variant CJD was announced in 2013 and confirmed by the National Prion Disease Pathology Surveillance Center (NPDPSC) in 2014.

Limited BSE testing by the USDA adds another layer to the already deepening concerns regarding possible risks to humans. In recent years, the USDA has decreased random testing for BSE from 40,000 to 25,000 tests per year (12,719 tests in 6 months, or 1 test per 3,302 live cows). Hence, surveillance of BSE in this country is largely dependent on demonstrating the lack of transmission to humans through human disease surveillance. The vCJD case identified by NPDPSC in 2014 exemplifies the persistent risk for vCJD acquired in unsuspected geographic locations and highlights the need for continuing prion surveillance and awareness to prevent further dissemination of vCJD.

CHRONIC WASTING DISEASE

Most recently, emerging laboratory data show that a prion disease of deer and elk called Chronic Wasting Disease (CWD) could potentially transmit to humans and other mammals, posing a new threat to public health. Human surveillance through brain tissue examination is the only way to definitely diagnose human prion diseases, determine their origin, and determine whether the spread of CWD found in elk and deer in 24 States in the U.S. and in 2 Canadian provinces has become a human risk. A study in progress has shown that CWD was transmitted to macaques (primates that are genetically similar to humans) by feeding them contaminated deer meat.

Unlike the BSE outbreak in cattle, CWD prions are highly infectious and the disease transmits by contact and through contaminated environment, including soil and plants. Additionally, multiple lines of experimental evidence indicate that sheep and cows are susceptible to CWD. Since CWD has been proven to cross the species barriers, this opens up the possibility of oral transmission to humans as well, either directly by eating contaminated venison or indirectly through infected domestic animals.

Additional concerns include widespread and long-term prion contamination of the environment given that prions can persist for decades and the vector of this illness (e.g., deer) are free ranging animals that are difficult to impossible to cull. Continued prion disease surveillance, particularly through examination of human brain tissue, is imperative to evaluate whether CWD has or can spread to humans. If transmissible to humans, the possibility of transmission between individuals via blood transfusions must also be investigated as transmission through blood is known to occur in vCJD. Hence now is not the time to remove funding for prion disease surveillance, rather it should be increased to appropriately deal with these emerging threats.

The NPDPSC, funded by the CDC and located at Case Western Reserve University in Cleveland, Ohio, is our line of defense against the possibility of an undetected U.S. human prion disease epidemic as experienced in the United Kingdom.

We ask for Congressional support in increasing the National Prion Disease Pathology Surveillance Center's (NPDPSC) appropriation for fiscal year 2020 by $2 million, for a total of $8 million. This would allow the NPDPSC to meet increasing autopsy costs and continue to develop more efficient detection methods while providing an acceptable level of human prion disease surveillance. Reduction of funding to the NPDPSC would eliminate an important safety net to U.S. public health, making the U.S. the only industrialized country lacking prion surveillance, which in turn would jeopardize the export of U.S. beef. The increase in funding would allow the NPDPSC to expand its scope to address the growth in Chronic Wasting Disease (CWD) among deer and elk, and explore whether CWD could spread to humans.

NATIONAL PRION DISEASE PATHOLOGY SURVEILLANCE CENTER

The NPDPSC is funded entirely by the CDC from funds allocated by Congress. The CDC traditionally keeps approximately half of the appropriation for CDC and State public health activities, and half goes to the NPDPSC.

Increasing the appropriation from $6.0M to $8.0M will allow the NPDPSC to persist and continue to develop more efficient detection methods while providing an acceptable level of prion surveillance. Acceptable national prion surveillance would not be possible at a lower level of funding. The requested $2.0M addition to the appropriation (total of $8.0M) would enable the NPDPSC to increase surveillance, tissue collection, diagnostics and diagnostic test development of prion disease cases from CWD endemic States to determine whether CWD is transmissible to humans and if so, to what extent this poses to public health (e.g., transmission risks from human to human).

The National Prion Disease Pathology Surveillance Center is the only organization in the U.S. that monitors human prion diseases and is able to determine whether a patient acquired the disease through the consumption of prion contaminated beef (“mad cow” disease) or meat from elk and deer affected by chronic wasting disease (CWD).

The NPDPSC also monitors all cases in which a prion disease might have been acquired by infected blood transfusion, from the use of contaminated surgical instruments or from contaminated human growth hormone. Because standard hospital sterilization procedures do not completely inactivate prions that transmit the disease, these incidents put a number of patients under unnecessary risk and required costly replacement of contaminated surgical equipment.

The NPDPSC also plays a decisive role in resolving suspected cases or clusters of cases of food-acquired prion disease that are often magnified by the media, stirring intense public alarm. To date, the NPDPSC has examined over 6,850 suspected incidents of suspected prion diseases and has definitely confirmed presence and type of prion disease in more than 4,100 cases.

The NPDPSC represents the primary line of defense in safeguarding U.S. public health against prion diseases because the United States—unlike other BSE affected countries such as the United Kingdom, the European Union, and Japan—does not have a sufficiently robust animal prion surveillance system.

The NPDPSC’s work offers assurances, to countries that import (or are considering importing) meat from the United States, that the U.S is free of indigenous human cases of “mad cow” disease. In recent years, South Korean and Chinese health officials resumed importation of U.S. beef to their country after a visit to the NPDPSC provided assurances regarding rigorous human prion surveillance.

Thank you for the opportunity to submit this testimony.

[This statement was submitted by Deborah R. Yobs, President/Executive Director, CJD Foundation and Brian S. Appleby, M.D., Medical Director, CJD Foundation, and Director, National Prion Disease Pathology Surveillance Center.]

PREPARED STATEMENT OF THE CURE ALZHEIMER’S FUND

Chairman Blunt, Ranking Member Murray, and members of the Senate Labor, Health & Human Services, Education, and Related Agencies Appropriations Subcommittee, I am Tim Armour, President and CEO of Cure Alzheimer’s Fund. I want to thank Congress for past funding for Alzheimer’s disease research at the National Institutes of Health (NIH), and to submit this written testimony to respectfully request at least an additional $350 million in fiscal year 2020 above the final enacted amount for fiscal year 2019 for Alzheimer’s disease research at the 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. Since its founding 15 years ago, Cure Alzheimer’s Fund has supported close to $90 million in research through nearly 400 projects. These Cure Alzheimer’s Fund supported projects are most often early stage research that are investigating novel ideas. Cure Alzheimer’s Fund has supported research ideas that have become more widely accepted such as vascular dysfunction and blood brain barrier impairments, the role of immune cells like microglia in the brain, and three-dimensional models to better exhibit brain changes and disease progression.

A sustained Federal investment, as the one established by this Subcommittee in recent years, allows Cure Alzheimer's Fund to support initial research that can then be supported by larger grants from the NIH. Continued investment in NIH presents opportunities for new ideas and researchers to be able to secure funding necessary for continued progress in unlocking the secrets of Alzheimer's disease.

This Subcommittee has demonstrated its commitment to Alzheimer's disease research at NIH through recent increases in the NIH budget. And for this commitment, Cure Alzheimer's Fund expresses its thanks and appreciation.

The ongoing support from this Subcommittee allows for organizations such as Cure Alzheimer's Fund to focus on early-stage research knowing that researchers will be able to seek NIH funder at a scale larger than Cure Alzheimer's Fund offers for individual projects. The "hand-off" from Cure Alzheimer's Fund to NIH is an important part of the process to getting therapeutic interventions tested, validated, and ultimately into the clinic to change the course of the disease for the millions of Americans and individuals around the world who are afflicted.

The continued Federal investment has allowed new ideas to be pursued. Ideas such as the role of viruses such as herpes in the development of Alzheimer's disease. Two independent studies supported by both NIH and Cure Alzheimer's Fund at the Icahn School of Medicine at Mount Sinai in New York and at Massachusetts General Hospital Harvard Medical School showed similar results.

https://www.cell.com/neuron/fulltext/S0896-6273(18)30421-5.

https://curealz.org/news-and-events/evidence-of-the-link-between-alzheimers-and-herpes-continues-to-grow/.

This type of independent, but collaborative research is vital to a better understanding of a disease as complex as Alzheimer's disease.

Additional resources have allowed research to be conducted into areas that will benefit not only patients living with Alzheimer's disease, but other neurological conditions as well. The role of neuroinflammation is gaining better understanding of its place in the development of Alzheimer's disease. There is growing consensus that to develop Alzheimer's disease, there needs to be an accumulation of beta amyloid, tau tangles, and neuroinflammation. Research supported by Cure Alzheimer's Fund is showing the role of neuroinflammation in other neurological conditions as well.

https://www.sciencedaily.com/releases/2018/07/180730145418.htm.

The relationship between Alzheimer's disease and other neurological conditions can be seen in the research being conducted into the possible application of a stroke medicine in preventing Alzheimer's disease. The drug currently in clinical trials to help the brain recover from stroke may also be able to help prevent Alzheimer's disease.

https://curealz.org/news-and-events/a-stroke-drug-in-clinical-trials-may-have-application-for-alzheimers-disease/.

As we learn more about the brain, we also learn more about Alzheimer's disease and visa-versa. Research is being conducted into the role of the lymphatic system in helping to clear the brain of debris. Jonathan Kipnis received the NIH Director's Pioneer Award for this research.

https://curealz.org/news-and-events/a-new-discovery-the-brain-has-a-drain-to-remove-debris/.

https://news.virginia.edu/content/uvas-jonathan-kipnis-receives-prestigious-nih-directors-pioneer-award.

Showing that the path to a cure for Alzheimer's disease may come from seemingly unlikely places, Cure Alzheimer's Fund supports research being conducted by Beth Stevens at Children's Hospital, Boston. Dr. Stevens' work on the development and elimanation of synapses at the early stages of brain development is being used to better understand this process at later stages in life. This research can be beneficial for not only Alzheimer's disease patients, but also for younger patients living with Autism Spectrum Disorders.

https://curealz.org/research/foundational-genetics/microglial-heterogeneity-and-transcriptional-state-changes-in-alzheimers-disease/.

Cure Alzheimer's Fund believes in funding science and research that has the best potential for leading us to a cure for Alzheimer's disease. This las lead Cure Alzheimer's Fund to supporting researchers such as Jonathan Kipnis and Beth Stevens who would not be considered traditional Alzheimer's disease researchers. Additionally, Cure Alzheimer's Fund has funded computer scientists who are working on the issues of data analysis. This becomes more important as more data sets are developed and need to be fully interpreted and understood.

https://curealz.org/researchers/andreas-pfenning/.

Cure Alzheimer's Fund is also supporting engineering efforts to help translate the scientific discoveries from the laboratory into practical tools to be used to further work toward a cure.

https://curealz.org/researchers/stephen-wong/.

Collaborations and supporting novel research are vital to a better understanding of the pathology of Alzheimer's disease and working toward a cure. The field has learned a great deal about Alzheimer's disease in the last few years, and this has been made possible because of the increased and sustained Federal investment in Alzheimer's disease research. If this continued commitment to increasing investment in Alzheimer's disease research is stopped or slowed, progress would not only be stopped or slowed, but even worse, it could retreat. Researchers who are considering focusing on Alzheimer's disease could leave the field. Researchers who are supported by organizations like Cure Alzheimer's Fund will have their initial data sets and proof of concept, but will not be able to secure the larger scale funding from NIH necessary to take their research to the next level.

Progress is being made in the fight against Alzheimer's disease. Partnerships between private organizations and NIH are leading to further discoveries and confirmation of theories. It is an exciting time in Alzheimer's disease research. This excitement is in no small part a result of the continued and sustain increased investment in Alzheimer's disease research supported and championed by this Subcommittee.

Cure Alzheimer's Fund thanks the Subcommittee for its continuing commitment to increasing funding for Alzheimer's disease. Cure Alzheimer's Fund values its partnership with NIH in Alzheimer's disease research, and the support of this Subcommittee has made that partnership more effective.

Thank you for the opportunity to submit this written testimony and to respectfully request at least an additional $350 million above the final enacted level in fiscal year 2019 for fiscal year 2020 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.

[This statement was submitted by Timothy Armour, President and CEO, Cure Alzheimer's Fund.]

Prepared Statement of Cure SMA

Cure SMA, the largest non-profit 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 on the critical importance of providing increased funding for the newborn screening (NBS) programs administered by HHS through the Health Resources Services Administration (HRSA) and the Centers for Disease Control and Prevention (CDC), and for the opportunity to request much needed funding for biomedical research for SMA at the National Institutes of Health (NIH) and its sub-agencies.

SMA OVERVIEW

SMA is an autosomal recessive neuromuscular disease caused by a mutation in the Survival Motor Neuron 1 (SMN1) gene that affects approximately 1 in 11,000 live births in the U.S., and an estimated 1 in 50 Americans is a genetic carrier. In a healthy individual, this gene produces a protein that is critical to the function of the nerves that control muscles. Without this protein, those nerve cells cannot function and eventually die, leading to debilitating and often fatal muscle weakness that robs patients of their ability to walk, eat, swallow or even breathe. However, SMA does not impact a patient's cognitive functioning.

Fortunately, there is an FDA-approved treatment, Spinraza, which became commercially available in December 2016. Administered through periodic intrathecal injections, it stimulates the SMN2 gene to act as a back up to the malfunctioning SMN1 gene and produce the protein needed for healthy muscle function. However, it cannot repair damaged motor neurons, only prevent or slow down damage, and therefore the treatment regime must begin as soon as possible.

Additionally, the FDA very recently approved another treatment, Zolgensma. This gene therapy replaces the faulty SMN1 gene with a healthy one, which then produces the necessary proteins. It is administered in a one-time IV dose, and like Spinraza, has shown the most benefits when administered as early as possible.

Recognizing the importance of early diagnosis and treatment in SMA, Health and Human Services Secretary Alex Azar added SMA to the Recommended Uniform Screening Panel (RUSP) last summer. The RUSP is a list of conditions that States are encouraged to include in their newborn screening (NBS) testing panels. As of May 2019, six States are permanently screening all newborns for SMA, and several others are expected to begin very shortly.

NEWBORN SCREENING

As mentioned above, early diagnosis is crucial to the best possible health outcome for someone with SMA. Ideally, treatment should start before symptoms appear, making NBS an important part of SMA care. Unfortunately, State programs are often slow to add new conditions to their testing panels because they lack the necessary funding and other resources. Given this, the number of conditions an infant is screened for at birth still varies greatly among 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 (NBBSLA) to reauthorize and expand the role of the Health Resources and Services Administration's (HRSA) Advisory Committee on Heritable Disorders in Newborns and Children program in developing national NBS guidelines, and to assist States in implementing comprehensive screenings. Prior to the law's passage, the number and quality of NBS tests varied greatly from State to State. Additionally, there was little to no guidance for States on the quality and validity of tests adopted for the screening of particular conditions.

While this law, and its 2014 reauthorization, have made tremendous strides in evening out this disparity, it still exists. States desperately need Federal resources to add the new equipment and staff needed to screen for new conditions, train staff on these new tests, and to establish the necessary follow up procedures should an infant test positive for a condition. In the case of SMA, several States have either passed legislation or taken regulatory action to add the condition to their panel but are unable to implement this screening because of a lack of resources.

Because newborn screening is so critical to effective treatment of SMA, we respectfully request the following:

HRSA Heritable Disorders Program: We ask Congress to provide $21.88 million in fiscal year 2020 to HRSA's Heritable Disorders Program to ensure infants born in every State receive rapid identification, early intervention, and the necessary treatment. In the 2014 reauthorization of the NBSSLA, Congress recognized the fundamental role of HRSA in coordinating and supporting a large number of complex activities including the in-depth scientific review of conditions nominated for the RUSP that cannot be replaced by programs at the State level. Furthermore, the agency plays a unique and essential role in coordinating stakeholders, including clinicians, hospitals, parents, patients, laboratories and public health professionals.

CDC Newborn Screening Quality Assurance Program: We ask Congress to provide $29.65 million to the Newborn Screening Quality Assurance Program (NSQAP) at the Centers for Disease Control and Prevention (CDC). This program is essential in supporting States in adopting and implementing new conditions to their testing panels through funding for laboratory equipment, supplies and staffing, as well as expert analysis and technical assistance. Such activities are imperative to ensure the quality and accuracy of these tests. The CDC is the only Federal agency that works alongside State laboratories to implement new tests and conduct ongoing work in these labs.

BIOMEDICAL RESEARCH

We applaud the recent increases in funding for the National Institutes of Health and ask that Congress continue this trend by increasing the fiscal year 2020 appropriation for NIH by $2 billion, bringing the total to $41.1 billion. We also ask that the National Institutes of Neurological Disorders and Stroke (NINDS) within NIH be funded at $2.3 billion, with special consideration to continuing research on SMA.

Dramatic increases in funding for NIH in recent years, both through the standard appropriations process and through the passage of the 21st Century Cures Act, have played a critical role in developing current SMA treatments, and in establishing the standard of care for SMA patients. However, much work remains to be done. We are immensely grateful for these breakthroughs, but we still need more effective and efficient treatments for all ages and stages of SMA. Both Spinraza and Zolgensma slow down or prevent motor neuron damage but cannot repair damage that has already happened. Due to the degenerative nature of SMA, older patients and those whose condition has worsened will need additional treatment options.

Within NIH, SMA has been traditionally been funded at a lower level than other genetic disorders with similar incidence. In order to improve the health outcomes of all SMA patients, there must be a continued focus on developing treatments for patients across the disease spectrum, particularly in adult patients. Congress must appropriate more funds, and encourage the necessary allocation, so that NINDS and NIH can continue their work to develop effective treatments for the entire SMA community.

CONCLUSION

Both robust newborn screening and continuing biomedical research are critical in the fight against this devastating disease and to alleviate its physical, emotional and financial impact. Therefore, we respectfully request $21.88 million for HRSA's Heritable Disorders Program, $29.65 million to CDC's Newborn Screening Quality Assurance Program, $41.1 billion for NIH, and $2.3 billion for NINDS.

Again, thank for the opportunity to provide testimony. We look forward to working with you to improve outcomes for SMA patients and their families across the Nation. For more information, please contact Jaimie Vickery, Vice President of Policy and Advocacy for Cure SMA, at jaimie.vickery@curesma.org.

PREPARED STATEMENT OF THE DIGESTIVE DISEASE NATIONAL COALITION

THE COALITION'S FISCAL YEAR 2020 L–HHS APPROPRIATIONS RECOMMENDATIONS

—$7.8 billion in program level funding for the Centers for Disease Control and Prevention (CDC).
  —$50 million for Colorectal Cancer Prevention.
  —$134 million for the Division of Viral Hepatitis.
  —$1 million for Inflammatory Bowel Disease.
—At least $41.6 billion in program level funding for the National Institutes of Health (NIH).
  —A proportional funding increase for the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK).

Chairman Blunt, Ranking Member Murray, and distinguished members of the Subcommittee, as you work to craft fiscal year 2020 appropriations for the Departments of Labor, Health and Human Services, Education, and related agencies, please consider the concerns of the digestive disease community. We hope you will support sustainable funding increases for the National Institutes of Health and the Centers for Disease Control and Prevention.

ABOUT THE COALITION

The Digestive Disease National Coalition (DDNC) is an advocacy organization comprised of the major national voluntary and professional societies concerned with digestive diseases. DDNC focuses on improving public policy and increasing public awareness with respect to diseases of the digestive system. DDNC's mission is to work cooperatively to improve access to and the quality of digestive disease healthcare in order to promote the best possible medical outcome and quality of life for current and future patients.

ABOUT DIGESTIVE DISEASES

Digestive diseases are disorders of the digestive tract, which includes the esophagus, stomach, small and large intestines, liver, pancreas, and the gallbladder; as such, these diseases range from digestive cancers to functional GI and motility disorders, and everything in between. Some of these diseases are classified as acute, as they occur over a short period of time, while others are chronic, life-long conditions. 60 to 70 million Americans are affected by these diseases, accounting for 21.7 million hospitalizations and $141.8 billion in healthcare costs.

CENTERS FOR DISEASE CONTROL AND PREVENTION

DDNC joins the public health community in asking Congress to provide the Centers for Disease Control and Prevention (CDC) with $7.8 billion through fiscal year 2020, which includes budget authority, the Prevention and Public Health Fund, Public Health and Social Services Emergency Fund, and PHS Evaluation transfers. The CDC houses a number of education and awareness activities that work to improve surveillance, diagnosis, and treatment for several digestive diseases, including colorectal cancer, inflammatory bowel disease (IBD), and viral hepatitis.

The Colorectal Cancer Control Program (CRCCP) helps States and tribes across the United States increase colorectal cancer screening rates among men and women aged 50 years and older, and an increase in these screenings will reduce illness and death from this cancer. Currently, the CRCCP funds 23 States, 6 universities, and one American Indian tribe. A proportional increase in funding will ensure that more vulnerable communities across the U.S. will gain the resources necessary to adhere to regular colorectal cancer screening.

The CDC has also led an epidemiological study of IBD to understand incidence, prevalence, demographics, and healthcare utilization. The study's goal is to learn more about the causes of IBD in order to improve care and target interventions. A modest increase in funding will allow CDC to improve treatments and diagnostics for patients with IBD, including Crohn's disease and ulcerative colitis.

The Division of Viral Hepatitis (DVH), in collaboration with domestic and global partners, provides the scientific and programmatic foundation and leadership for the prevention and control of hepatitis virus infections and their manifestations. Its three branches, Epidemiology and Surveillance, Prevention, and Laboratory, work to prevent viral hepatitis infections and associated liver disease. Increases in funding for DVH will allow the Division to achieve the imperatives, objectives, and strategies outlined in its 5-year strategic plan to decrease disease incidence, morbidity and mortality, and health disparities.

NATIONAL INSTITUTES OF HEALTH

DDNC joins the medical research community in thanking Congress for continuing to support the National Institutes of Health. In fiscal year 2020, please continue to provide sustainable growth at the Institutes by providing the NIH with at least a $2.5 billion funding increase to bring total funding up to $41.6 billion. Strengthening the Nation's biomedical research enterprise through NIH fosters economic growth and sustains innovations that enhance the health and well-being of the American people. In this regard, please also provide a proportional increase for the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK). NIDDK supports basic, translational, and clinical research into various diseases such as inflammatory bowel disease (IBD), pancreatic cancer, gastroparesis, and others. This federally-funded research often serves as a catalyst with industry turning medical breakthroughs and scientific advancements into innovative therapies and cutting-edge diagnostic tools.

Thank you for your time and consideration of our requests, and we look forward to continuing to work with you on these issues.

[This statement was submitted by Samir Shah, MD, FACG, FASGE, AGAF, President, Digestive Disease National Coalition.]

PREPARED STATEMENT OF DR. STEFANO GUANDALINI AND DR. BANA JABRI OF THE UNIVERSITY OF CHICAGO

Chairman Blunt, Ranking Member Murray and distinguished Members of the Subcommittee, thank you for the privilege of submitting written testimony.

Celiac disease is a serious autoimmune disease that is not being taken seriously enough by our government.

Celiac disease is one of the world's most common genetic autoimmune diseases. Approximately 40 percent of us carry the genetic marker and about 1 percent of us actually develop celiac disease. Yet, this is nearly double the number of people with Crohn's disease and ulcerative colitis combined, and nearly triple the number of those with Type 1 Diabetes.

And, regrettably, researchers are finding that the disease prevalence is doubling approximately every 15 years, making it a public health epidemic.

It is estimated that no more than 40 percent of the 3 million Americans with celiac disease have been correctly diagnosed. The other almost 2 million continue to suffer and have no idea why. In celiac disease patients, gluten, a protein found in wheat, barley and rye, triggers an immune response leading the body to attack the small intestine.

This intestinal damage causes more than 200 debilitating symptoms. Moreover, gluten ingestion for people with celiac disease causes permanent immunological scarring, doubles the risk of heart disease, and acts as a carcinogen, quadrupling the risk of small intestinal cancers.

Strict adherence to a gluten-free diet is the only available treatment. But, as our celiac disease researchers agree, "There is no such thing as a truly gluten-FREE diet" because of the constant risk of cross-contact with gluten, and gluten is in 80 percent of our foodstuffs.

It is imperative that celiac disease be recognized as an important threat to the health of our citizens by the U.S. Government, including and especially by the NIH, the FDA, the CDC, and CMS. Celiac disease research receives virtually no investment from the private sector, and little to no resources from NIH, especially when compared to diseases with similar impact.

Celiac disease is very serious:

—The lifetime burden of the gluten-free diet is perceived by patients to be second only to end-stage renal disease, and by caregivers, comparable to caring for a patient with cancer.

—Our diagnosed patients report that they miss, on average, 23 days of work and school annually, resulting in excess utilization of our healthcare resources.

Thank you for your time today and thank you for anything this distinguished Subcommittee can do to assist us in this fight to end this serious disease.

PREPARED STATEMENT OF THE DYSTONIA MEDICAL RESEARCH FOUNDATION

SUMMARY OF RECOMMENDATIONS FOR FISCAL YEAR 2019

—Provide $41.6 billion for the National Institutes of Health (NIH) and proportional increases across its Institutes and Centers

—Continue dystonia research supported by NIH through the National Institute on Neurological Disorders and Stroke (NINDS), the National Institute on Deafness and other Communication Disorders (NIDCD), and the National Eye Institute (NEI).

Dystonia is a neurological movement disorder characterized by involuntary muscle spasms that cause the body to twist, repetitively jerk, and sustain postural deformities. Focal dystonia affects specific parts of the body, while generalized dystonia affects multiple parts of the body at the same time. Some forms of dystonia are genetic but dystonia can also be caused by injury or illness. Although dystonia is a chronic and progressive disease, it does not impact cognition, intelligence, or shorten a person's life span. Conservative estimates indicate that between 300,000 and 500,000 individuals suffer from some form of dystonia in North America alone. Dystonia does not discriminate, affecting all demographic groups. There is no known cure for dystonia and treatment options remain limited.

Although little is known regarding the causes and onset of dystonia, two therapies have been developed that have demonstrated a great benefit to patients and have been particularly useful for controlling patient symptoms. Botulinum toxin (e.g., Botox, Xeomin, Disport and Myobloc) injections and deep brain stimulation have shown varying degrees of success alleviating dystonia symptoms. Until a cure is discovered, the development of management therapies such as these remains vital, and more research is needed to fully understand the onset and progression of the disease in order to better treat patients.

DYSTONIA RESEARCH AT THE NATIONAL INSTITUTES OF HEALTH

The Dystonia Medical Research Foundation urges the Subcommittee to continue its support for natural history studies on dystonia that will advance the pace of clinical and translational research to find better treatments and a cure. In addition, we encourage Congress to continue supporting NINDS, NIDCD, and NEI in conducting and expanding critical research on dystonia.

Currently, dystonia research at NIH is supported by the National Institute of Neurological Disorders and Stroke (NINDS), the National Institute on Deafness and Other Communication Disorders (NIDCD), and the National Eye Institute (NEI).

The majority of dystonia research at NIH is supported by NINDS. NINDS has utilized a number of funding mechanisms in recent years to study the causes and mechanisms of dystonia. These grants cover a wide range of research including the genetics and genomics of dystonia, the development of animal models of primary and secondary dystonia, molecular and cellular studies in inherited forms of dystonia, epidemiology studies, and brain imaging. We along with NINDS recently held a meeting with the goal of to define emergent opportunities in dystonia research. The meeting brought together key individuals actively involved in genetic, cellular, physiological, systems and clinical research on dystonia and other relevant research areas, to discuss existing and potential possibilities to refocus and accelerate dystonia research as well as assess the most optimal ways to transfer recent basic science findings to clinical practice. The meeting provided a unique opportunity to assess the dystonia research agenda, stimulate more integrative and cross-disciplinary approaches, and provide recommendations for the next decade of research support and funding. The meeting took place more than 10 years since the previous major joint meeting also hosted by NINDS in 2006.

The primary outcomes of the meeting are: (a) a summary of the status of dystonia research with a special emphasis on emerging trends (a publication summarizing the meeting is in preparation), (b) identification of research areas that need to be supported in order to develop more solid scientific basis for better understanding dystonia etiology and treatment; (c) identification and evaluation of the current status of translational dystonia research; (d) identification of traditionally 'non-dystonia' research areas that have the potential to substantially contribute to the dystonia field; (e) identification of dystonia patients' therapeutic needs and assessment of clinical relevance of current and future dystonia studies.

It is of great significance that a number of dystonia patient advocacy group, led by the Dystonia Medical Research Foundation, actively took part in the meeting and are working to ensure that Congress continues to support robust NIH funding.

NIDCD and NEI also support research on dystonia. NIDCD has funded many studies on brainstem systems and their role in spasmodic dysphonia, or laryngeal dystonia. Spasmodic dysphonia is a form of focal dystonia which involves involuntary spasms of the vocal cords causing interruptions of speech and affecting voice quality. NEI focuses some of its resources on the study of blepharospasm. Blepharospasm is an abnormal, involuntary blinking of the eyelids which can render a patient legally blind due to a patient's inability to open their eyelids. We were pleased to see that Congress has encouraged both NIDCD and NEI to expand their research into both spasmodic dysphonia and belpharospasm.

We thank the committee for the increase for NIH in fiscal year 2019. We know firsthand that this will further NIH's ability to fund meaningful research that benefits our patients.

PATIENT PERSPECTIVES

My dystonia first presented when I was about 8 years old and my parents took me to many, many doctors. My foot and leg would turn in when I tried to walk—making walking very difficult. The kids at school would tease me and called me names like “mental foot”. When I couldn't explain it, they teased me more. Finally, at the age of 12 the diagnosis of dystonia was made. I have the genetic form of dystonia—DYT1 dystonia that is generalized and commonly affects children between the ages of 8 to 15. For me, dystonia spread from my left foot to both legs, my arms and my back. When I walked, my back would arch and put a lot of pressure on the bottom of my spine which was pretty painful. My legs were very tight. My right foot started to turn in and that put pressure on my ankle when I walked. My right arm was very tight, so when I had to write it was painful. I decided to pursue Deep Brain Stimulation for my dystonia when it became too painful to walk with my son to the park that was around the corner from our house. The results have been life-changing. My wife and sons now have a husband and father who, despite having dystonia, is physically able to be active and a part of their lives. It isn't a cure but a treatment that really worked for me.

I drive through Atlanta's brutal traffic when suddenly, my eyes clamp shut. I pry my left eye open with thumb and forefinger, steer with my right hand. My eyes open for a few seconds, then close with no warning. What is happening? Over the next few months, these spasms progress from eyes to lower face, neck and shoulders. A year later I am diagnosed with Dystonia, a debilitating, little-known disease. A healthy 49-year-old mother of three, I now fight constant pain; can no longer work, drive or perform basic activities. Even walking our dog is a dangerous fall risk.

Spasmodic dysphonia (SD), a focal form of dystonia, is a neurological voice disorder that involves “spasms” of the vocal cords causing interruptions of speech and affecting voice quality. My voice sounds strained or strangled with breaks where no sound is produced. When untreated, it is difficult for others to understand me. I receive injections of botulinum toxin into my vocal cords every 3 months for temporary relief of symptoms. This has worked well for me for over a decade. At the start of this year, my insurance coverage changed when my husband's company changed providers. As a result, I had to undergo an extensive review process and change methods for obtaining my medicine. The review lasted for four weeks. Multiple times during this time period, my doctor and I were told that I had been denied coverage. After a seven week delay, I am scheduled for my injection and am looking forward to a period of spasm-free speaking.

DMRF was founded in 1976. Since its inception, the goals of DMRF have remained to advance research for more effective treatments of dystonia and ultimately find a cure; to promote awareness and education; and support the needs and wellbeing of affected individuals and their families.

Thank you for the opportunity to present the views of the dystonia community, we look forward to providing any additional information.

[This statement was submitted by Janet Hieshetter, Executive Director, Dystonia Medical Research Foundation.]

PREPARED STATEMENT OF THE EDUCATION TRUST

On behalf of The Education Trust, an organization dedicated to closing longstanding gaps in opportunity and achievement separating students from low-income backgrounds and students of color from their peers, thank you for the opportunity to present testimony on the fiscal year 2020 Labor, Health and Human Services, Education and Related Agencies (L–HHS–ED) Appropriations bill.

Before discussing specific appropriations priorities, the Education Trust would like to highlight our support for the substantial increase of statutory budget caps for fiscal year 2020 and 2021, specifically to prevent damaging cuts to non-defense discretionary (NDD) spending. Within those increased caps, the Labor–HHS–ED appropriations bill should remain a priority and receive, at minimum, an increase proportional to the overall NDD increase.

While there are many programs under your jurisdiction that are critical to advancing equity, for fiscal year 2020, The Education Trust is focused on the following: strengthening the Pell Grant program by increasing the maximum award to at least $6,345; supporting teachers and school leaders by level funding ESSA's Title II–A ($2.055B), the Teacher and School Leader Incentive Program ($200 million), the Supporting Effective Educator Development Program ($75 million), HEA's Title II's Teacher Quality Partnership grants ($43.1M); and restoring funding to the School Leader Recruitment and Support Program ($14.5M). We are encouraged by the funding levels provided by the House Subcommittee on Labor, Health and Human Services, Education and Related Agencies (L–HHS–ED) for some of these initiatives and urge continued support for these critical programs.

STRENGTHENING THE PELL GRANT PROGRAM

The Pell Grant program is the cornerstone of Federal financial aid. Created in 1972 as the Basic Educational Opportunity Grant, the program benefits over 7 million students annually and continues to serve as the primary Federal effort to open the door to college for students from low-income backgrounds. Over one-third of White students, two-thirds of Black students, and half of Latino students rely on Pell Grants every year.[1] Pell Grant dollars are well-targeted to those in need: 83 percent of Pell recipients come from families with annual incomes at or below $40,000, including 44 percent with annual family incomes at or below $15,000.[2]

Increasing the Maximum Award

The Pell Grant program's impact is shrinking as the maximum award has failed to keep pace with the rapidly rising cost of college. The purchasing power of the Pell Grant has dropped dramatically since the program's inception. In 1980, the maximum Pell Grant award covered 76 percent of the cost of attendance at a public university. Today, it covers just over 28 percent, the lowest portion in over 40 years. If the maximum award continues to stagnate, the grant will cover just one-fifth of college costs in 10 years.

We very much appreciate previous increases to the maximum award in prior omnibus appropriations bill, and we respectfully request that you continue to increase the maximum award amount. For fiscal year 2020, Congress should increase the maximum award to at least $6,345 to keep pace with inflation. We also ask Congress to use HEA reauthorization to enact an ambitious plan to reverse the downward trend of Pell's purchasing power through proscribed funding increases and expansion of the mandatory funding stream, ensuring that the maximum Pell award covers at least half of the cost of attendance at a public 4-year institution.

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[1] Congressional Budget Office (CBO), January 2017 baseline projections for the Pell Grant program, http://bit.ly/2mLy0nk, Table 2; and Ed Trust calculation NPSAS:12 using PowerStats.

[2] https://www2.ed.gov/finaid/prof/resources/data/pell-data.html.

SUPPORTING TEACHERS AND SCHOOL LEADERS

Research and experience show the powerful impact that teachers and school leaders have on student learning. ESSA's Title II program provides grants to States and districts that can be used to invest in the education profession. These funds can be used to, among other things, address inequities in access to effective teachers and school leaders, provide professional development, and improve teacher recruitment and retention. States and districts can also apply for additional competitive grant dollars for programs targeted at specific, evidence-based strategies for improving teacher and school leader effectiveness and increasing educator diversity. Additionally, HEA's Title II's Teacher Quality Partnership grants (TQP), awarded to partnerships of high-need districts and teacher preparation programs at institutions of higher education, can be used to recruit underrepresented populations to the teaching profession. As Ed Trust's work continues to demonstrate the positive impact that diverse teachers and school leaders of color can have on the academic achievement of both students of color and White students, we remain supportive of Federal dollars to increase and bolster the diversity of the educator pipeline.

Maintain funding for ESSA Title II–A (Supporting Effective Instruction), the Teacher and School Leader Incentive Program (TSLIP), the Supporting Effective Educator Development (SEED) program, and HEA Title II Teacher Quality Partnership (TQP) grants

Despite the nationwide attention to the need to invest in educators, the President's fiscal year 2020 budget request again called for the elimination of the Title II–A grant, the SEED program, and HEA Title II Teacher Quality Partnership grants. We appreciate Congress' rejection of these requests in the fiscal year 2019 omnibus appropriations bill. At a minimum, in fiscal year 2020, Congress should continue funding Title II–A, TSLIP, SEED, and TQP at fiscal year 2019 levels: $2.055B, $200 million, $75 million, and $43.1M, respectively.

Restore Funding for the School Leader Recruitment and Support Program

Landmark research funded by the Wallace Foundation has found "virtually no documented instances of troubled schools being turned around without intervention by a powerful leader," and the School Leader Recruitment and Support Program is the only Federal program specifically focused on investing in evidence-based, locally driven strategies to strengthen school leadership in high-need schools. A recently concluded 7-year study of school districts that created pipelines to develop school leaders saw increasing gains in student achievement over time, showing how a sustained initiative can demonstrate positive effects on student learning.

During the past decade, we have learned a lot about what works in education leadership-lessons made possible, in part, by Federal investments in the School Leader Program (the previous iteration of the SLRSP). There is still a great deal of work to do, especially when it comes to identifying and efficiently preparing effective turnaround leaders, as well as sustainably supporting them to accelerate academic achievement, close gaps, and maintain improvement over time for all students and in every community. The SLRSP is a key lever for seeding the next generation of effective school leader development programs, promoting equity, advancing ongoing innovation, and sharing cutting-edge lessons on transformational leadership with the broader field.

For fiscal year 2020, Congress should restore funding for the School Leader Recruitment and Support Program to $14.5M, its fiscal year 2017 appropriation level.

Thank you for the opportunity to submit testimony, and The Education Trust is happy to respond to any questions or concerns.

[This statement was submitted by John B. King Jr., President and CEO, The Education Trust.]

PREPARED STATEMENT OF THE ELDER JUSTICE COALITION

Chairman Blunt, Ranking Member Murray:

On behalf of the bipartisan 3000-member Elder Justice Coalition, I thank you for your past support of programs designed to end the ravages of elder abuse, neglect, and exploitation in America. Thank you also for the honor of presenting the EJC viewpoints to the Subcommittee last year. I submit this fiscal year 2020 testimony in support of funding in the Department of Health and Human Services for several programs that play unique roles in addressing elder abuse.

The EJC request includes $25 million under the Administration for Community Living (ACL) Elder Justice Initiative and $25 million in dedicated funding for Adult Protective Services authorized under the Elder Justice Act; $20 million in additional targeted funding for the State Long-Term Care Ombudsman Program in Title VII of the Older Americans Act to address assisted living quality of care; $17 million for Title VII core long-term care ombudsman services; and $5 million for Title VII Programs for Prevention of Elder Abuse, Neglect, and Exploitation. Also, we request $5 million for supporting effective community-based education and awareness programs and training for the ombudsman program as authorized under the Elder Justice Act, and no less than $1.7 billion under the HHS Administration for Children and Families (ACF) Social Services Block Grant. I also testify in support of at least $5 million for the OAA aging network to address the growing demand for a coordinated response to abuse linked to the opioid addiction of family and caregivers of older adults, and for $250,000 in new funding for an Advisory Board on Elder Abuse, Neglect, and Exploitation, called for in the Elder Justice Act, but never funded. Further, I testify in support of increasing oversight on the Centers for Medicare and Medicaid Services (CMS).

Thank you again for your leadership with difficult budget issues in recent years. Broadly speaking, we ask that you again come to bipartisan agreement on budget caps for fiscal years 2020 and 2021. The EJC views this as a necessity and as an opportunity to secure important new funding increases for elder justice programs which will prevent and address elder abuse, neglect, and exploitation that is growing in each of our communities.

The national menace of elder abuse continues. The Justice Department estimates one in ten older adults will experience abuse annually. In fact, close to 50 percent of people with dementia will be abused. Financial abuse alone costs its older victims $2.9 billion a year. The direct medical costs of injuries and care related to elder abuse exceed $5 billion a year. And, as the Senate Special Committee on Aging has found, for every reported case of abuse, there are five times as many that go unreported.

As you know, no State is immune from the horrible storied of abuse reported in our neighborhoods and in long-term care facilities, including everything from physical and sexual abuse of older adults in their own homes or living in assisted living and nursing homes to neglect leading to starvation and bed sores to stealing assets from older persons and leaving them in poverty and or homeless. Sadly, we can read about these crimes every day in newspapers and on line from across the county.

Unfortunately, our Federal response fails to meet even a common-sense approach to a problem that is costing the Nation so much in diminished quality of life, additional healthcare expenditures, caregiver crises, and law enforcement actions. The specific fiscal year 2020 asks of our bipartisan Coalition to address this worsening situation are:

—$25 million in funding for the Elder Justice Initiative in ACL. As the Federal home for Adult Protective Services (APS), ACL needs these funds to continue to advance the first national APS system with centralized and improved data collection, including data on abuse linked to opioid and similar drug addiction. The Initiative also supports innovation grants for elder abuse prevention, funds for elder abuse forensics needed in the prosecution of perpetrators, and abuse education and prevention in Indian Country. Also, $25 million is requested in dedicated funding for Adult Protective Services authorized under the Elder Justice Act.

—$25 million in additional funding for Title VII of the Older Americans Act, of which $20 million would be for the Long-Term Care Ombudsman Program to improve their capacity in two new areas of critical concern: to prevent and address abuse in assisted living, a problem identified in a February 2018 GAO report as a growing concern, and to respond to the opioid crisis in nursing homes. The remaining $5 million could be directed at supporting effective community-based education and awareness programs and training.

—$17 million in current core funding for the State Long-Term Care Ombudsman Program focused on nursing home quality of care and residents' rights.

—At least $1.7 billion in funding for the Social Services Block Grant, but preferably an increase. This block grant has not seen new funding since 1999, and it is being stretched thin across several dozen worthy programs that all need additional resources. This block grant is the only Federal funding provided for Adult Protective Services (APS), and it also funds other community-based programs that serve elder abuse victims, such as home-delivered meals.

—$250,000 to convene the Advisory Board on Elder Abuse, Neglect, and Exploitation, called for in the Elder Justice Act, to complement the work of the Elder Justice Coordinating Council, so ably supported by ACL Administrator Lance Robertson of Oklahoma.

—This year we also ask that you provide to ACL at least $5 million from the billions that Congress has appropriated to address opioid addiction. We strongly advocate that ACL be one of the HHS operating divisions to receive funds. These funds would be used to support the aging network's need for coordination, collaboration, data collection, referrals, and particularly training to address elder abuse tied to opioid addiction that has been recently documented. These funds would be directed toward vulnerable older victims of opioid-based elder abuse who have been overlooked to date. Specific resources are needed in our communities for the aging network, APS, the ombudsmen, law enforcement, and others to develop plans

—Finally, we ask for vigorous oversight of CMS to ensure no further rollbacks in regulations aimed at protecting nursing home residents and that they respond in a timely manner to reports of abuse in long-term care facilities, lengthy time-frame failures that were identified last year in a recent HHS Inspector General report.

Elder justice should be more than an aspiration. It helps define quality of life for an older adult, which can never be achieved while there is elder abuse. Its prevention must be our national mission. Thank you for considering our request.

[This statement was submitted by John B. Breaux, Honorary Chair and Robert B. Blancato, National Coordinator, Elder Justice Coalition.]

PREPARED STATEMENT OF THE ENDOCRINE SOCIETY

The Endocrine Society thanks the Subcommittee for the opportunity to submit the following testimony regarding fiscal year 2020 Federal appropriations for biomedical research and public health programs. The Endocrine Society is the world's oldest and largest professional organization of endocrinologists representing more than 18,000 members worldwide. The Society's membership includes basic and clinical scientists who receive support from the National Institutes of Health (NIH) to fund research on endocrine diseases that affect millions of Americans, such as diabetes, thyroid disorders, cancer, infertility, aging, obesity and bone disease. Our membership also includes clinicians who depend on new scientific advances to better treat and cure these diseases. Our organization is dedicated to promoting excellence in research, education, and clinical practice in the field of endocrinology. To support necessary advances in biomedical research to improve health, the Endocrine Society asks that the NIH receive total funding of least $41.6 billion for fiscal year 2020. To facilitate the translation of these advances to improve public health, the Endocrine Society asks that the Centers for Disease Control (CDC) receive funding of at least $7.8 billion; and to ensure that women have access to appropriate health services, we recommend that the Title X program be funded at $400 million.

ENDOCRINE RESEARCH IMPROVES PUBLIC HEALTH

Sustained investment by the United States Federal Government in biomedical research has dramatically advanced the health and improved the lives of the American people. The United States' NIH-supported scientists represent the vanguard of researchers making fundamental biological discoveries and developing applied therapies that advance our understanding of, and ability to treat human diseases. Their research has led to new medical treatments, saved innumerable lives, reduced human suffering, and launched entire new industries.

Endocrine scientists are a vital component of our Nation's biomedical research enterprise and are integral to the healthcare infrastructure in the United States. Endocrine Society members study how hormones contribute to the overall function of the body and how the glands and organs of the endocrine system work together to keep us healthy. Consequently, endocrine research contributes an important understanding of how the various systems of the human body communicate and interact to maintain health. The multiple body functions governed by the endocrine system are broad and essential to overall wellbeing: endocrine functions include reproduction, the body's response to stress and injury, sexual development, energy balance and metabolism, and bone and muscle strength. Endocrinologists also study interrelated systems, for example how hormones produced by fat can influence the development of bone disease and susceptibility to infections.

ENDOCRINE RESEARCH IS SUPPORTED BY NUMEROUS NIH INSTITUTES

Many endocrine diseases and disorders are addressed by the missions of multiple NIH Institutes and Centers (ICs); research on all biological systems and disease States is necessary to advance effective therapies for these diseases. For example:

—Endocrine researchers funded by the National Institute of Aging help us understand how hormonal treatment for menopause might improve stress responses in women;[1]

—Researchers funded by the Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD) are discovering how hormones influence the gut microbiome, which in turn can influence the development of polycystic ovarian syndrome (PCOS).[2]

—Endocrine oncologists supported by the National Cancer Institute developed a new drug with a unique mechanism that could inhibit the growth of drug-resistant prostate cancer.[3]

—Diabetologists funded by the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) are exploring new genes and biological pathways that could prevent or reverse the development of diabetes.[4]

—National Institute of Environmental Health Science (NIEHS)-funded researchers are investigating how per- and polyfluoroalkyl substances can disrupt endocrine systems resulting in reproductive and cognitive health effects.[5]

An effective biomedical research enterprise therefore requires a strong base appropriation for the NIH and sustained support for all ICs.

NIH REQUIRES STEADY, SUSTAINABLE FUNDING INCREASES

The Endocrine Society appreciates the increases to the NIH budget in recent fiscal years; however, the biomedical research community requires steady, sustainable increases in funding to ensure that the promise of scientific discovery can efficiently be translated into new cures. NIH grant success rates are predicted to remain 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 know that when laboratories lose financing; they lose people, ideas, innovations and new patient treatments.[6]

ADEQUATE FUNDING OF CDC PROGRAMS IS NECESSARY TO PROTECT THE PUBLIC'S HEALTH

The CDC plays a critical role in advancing public health by applying new knowledge to the promotion of health and prevention of epidemic diseases such as diabetes. The Division of Diabetes Translation administers the National Diabetes Prevention Program (National DPP), which addresses the increasing burden of prediabetes and Type 2 Diabetes in the United States. The National DPP creates public and private partnerships to provide evidence-based, cost-effective interventions that prevent diabetes in community-based settings. Through structured lifestyle change programs at local YMCAs or other community centers, individuals with prediabetes can reduce the risk of developing diabetes by 58 percent in those under 60 and by 71 percent in those 60 and older.[7] In addition to supporting public health and prevention activities, CDC's Clinical Standardization Programs in the Center for Environmental Health are critical to improving accurate and reliable testing of hormones, appropriate diagnosis and treatment of disease, and reproduceable public health research. Adequate funding is critically important to ensure that CDC has the capacity to address existing and emerging threats to public health in the United States and around the world.

TITLE X FUNDING PROVIDES NECESSARY SERVICES AND REDUCES HEALTHCARE COSTS

Title X is an important source of funding for ensuring reproductive health benefits including both contraceptive and preventive services to women. In 2015, a study

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[1] https://www.endocrine.org/news-room/press-release-archives/2017/treating-menopausal-symptoms-can-protect-against-stress-negative-effects Accessed March 11, 2018.

[2] Torres, PJ, et al., "Gut Microbial Diversity in Women with Polycystic Ovary Syndrome Correlates with Hyperandrogenism" The Journal of Clinical Endocrinology & Metabolism, jc.2017–02153.

[3] https://www.endocrine.org/news-room/press-release-archives/2013/new-medication-treats-drug-resistant-prostate-cancer-in-the-laboratory. Accessed March 11, 2018.

[4] Cinti, F, et al., Evidence of β-Cell Dedifferentiation in Human Type 2 Diabetes. The Journal of Clinical Endocrinology & Metabolism, Volume 101, Issue 3, 1 March 2016, Pages 1044–1054.

[5] Vuong, A., et al., "Prenatal and childhood exposure to poly- and perfluoroalkyl substances (PFAS) and cognitive development in children at age 8 years." Environmental research. 2019 Feb 16; 172 :242–248.

[6] Teresa K. Woodruff "Budget Woes and Research." The New York Times. September 10, 2013.

[7] The Diabetes Prevention Program (DPP) Research Group "The Diabetes Prevention Program (DPP): description of lifestyle intervention." Diabetes Care. 2002 Dec;25(12):2165–71.

found that Title X-funded health centers prevented 822,000 unintended pregnancies, resulting in savings of $7 billion to Federal and State Governments. Offering affordable access to contraception can have a measurable impact on these costs. For every public dollar invested in contraception, short-term Medicaid expenditures are reduced by $7.09 for the pregnancy, delivery, and early childhood care related to births from unintended pregnancies, resulting in savings of $7 billion to Federal and State Governments.[8]

Title X is the main point of care for low income, under- or un-insured, adults and adolescents for affordable contraception, cancer screenings, sexually transmitted disease testing and treatment, and medically-accurate information on family planning options. However, to provide these services to the over 4 million people who depend on Title X-funded centers, Title X is significantly underfunded.

FISCAL YEAR 2020 FUNDING REQUESTS

In conclusion, to avoid loss of promising research opportunities, allow budgets to keep pace with inflation, support public health infrastructure , and assure high-quality, evidence-based, and patient-centered family planning care, the Endocrine Society recommends that the Subcommittee provide at least the following funding amounts through the fiscal year 2020 Labor, Health and Human Services, Education, and Related Agencies appropriations bill:

—$41.6 billion for the National Institutes of Health
—$7.8 billion for the Centers for Disease Control and Prevention
—$400 million for Title X

Prepared Statement of Entomological Society of America

The Entomological Society of America (ESA) respectfully submits this statement for the official record in support of funding for insect-borne disease research at the U.S. Department of Health and Human Services (HHS). ESA requests $41.6 billion in fiscal year 2020 for the National Institutes of Health (NIH), including increased support for insect-borne disease research at the National Institute of Allergy and Infectious Diseases (NIAID). The Society also supports increased investment in the core infectious diseases budget and the global health budget within the Centers for Disease Control and Prevention (CDC) to fund scientific activities related to vector-borne diseases for a total of $7.8 billion in fiscal year 2020. ESA also requests Congress provide full funding for the Institute of Museum and Library Services (IMLS), including $38.6 million in fiscal year 2020 for the Office of Museum Services.

NIH, the Nation's premier medical research agency, advances human health by supporting research on basic human and pathogen biology and by developing prevention and treatment strategies. Cutting-edge research in the biological sciences, including the field of entomology, is essential for addressing societal needs related to environmental and human health. Many species of insects and arachnids (including ticks and mites) serve as carriers, or vectors, of an array of infectious diseases that threaten the health and well-being of people across the globe. This threat impacts citizens in every State and territory of the U.S. and military personnel serving at home and abroad. The mosquitoes that vector diseases are considered responsible for the deaths of more people than all other animal species combined, including humans.[1] Vector-borne diseases can be particularly challenging to control; controlling the insect and arachnid vectors is complicated by their mobility and their propensity for developing pesticide resistance. Further, effective vaccines are not available for many of these diseases.

Within NIH, NIAID conducts and supports fundamental and applied research related to the understanding, prevention, and treatment of infectious diseases. The risk of emerging infectious diseases grows as global travel increases in speed and frequency and as environmental conditions conducive to population growth of vectors, like mosquitoes and ticks, continue to expand globally. Entomological research aimed at understanding the relationships between insect vectors and the diseases they transmit is essential for reliable monitoring and prediction of outbreaks, effective prevention of disease transmission, and rapid diagnosis and treatment of diseases. For example, NIAID researchers at the NIH recently discovered that flaviviruses reproduce in tick salivary glands.[2] The most notorious of flaviviruses in-

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[8] Frost JJ, et al., Publicly Funded Contraceptive Services at U.S. Clinics, 2015, New York: Guttmacher Institute, 2017.

[1] https://www.gatesnotes.com/Health/Most-Lethal-Animal-Mosquito-Week.

[2] https://www.niaid.nih.gov/news-events/nih-scientists-explore-tick-salivary-glands-tool-study-virus-transmission-and-infection.

clude the viruses that cause dengue fever, Zika, West Nile, yellow fever, and Powassan. The Powassan virus is the only disease-inducing flavivirus that is endemic to North America and is a re-emerging virus that is very rapidly transmitted by ticks. By identifying that these viruses reproduce in the salivary glands in ticks, scientists have identified a possible explanation for the high speed in which transmission of this virus between the vector and the host takes place. This breakthrough will aid in the identification of transmission pathways which can then be used to eliminate this tick-borne flavivirus disease as more information becomes available. Given the enormous impact of insect carriers of disease 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.

CDC, serving as the Nation's leading health protection agency, conducts scientific research and provides health information to prevent and respond to infectious diseases and other global health threats, irrespective of whether they arise naturally or via acts of bioterrorism. Within the core infectious diseases budget of CDC, the Division of Vector-Borne Diseases (DVBD) aims to protect the Nation from the threat of viruses and bacteria transmitted primarily by mosquitoes, ticks, and fleas. DVBD's mission is carried out by a staff of experts in several scientific disciplines, including entomology.

CDC plays a key role in tracking new and emerging diseases. Dengue fever, limited 50 years ago to a small region in Southeast Asia, has now spread across several continents and results in about 500,000 deaths per year.[3] Chikungunya fever, once constrained to eastern African, has now spread across the globe with Chikungunya infection rates surpassing that of dengue in the Caribbean.[4] Both diseases are spread by mosquito vectors that occur widely in the southern U.S. The first cases of Chikungunya locally acquired in Florida were reported in the last decade, and both viruses threaten to spread further into the U.S., especially in the face of changing climate conditions. Funding for research on what effects population dynamics of the primary vector, the yellow fever mosquito (Aedes aegypti), is critical to developing strategies for stemming the spread of these diseases and preventing a major public health crisis.

CDC has also awarded nearly $50 million to five universities to establish regional centers of excellence (COE) that can help effectively address emerging and exotic vector-borne diseases. The five centers, for which current funding expires in 2021, help generate the necessary research, knowledge, and capacity to enable appropriate and timely local public health action for vector-borne diseases throughout the U.S. This is critical given significant regional differences in vector ecology, disease transmission dynamics and resources. One recent breakthrough, supported by the Southeastern COE in Vector Borne Diseases, used CRISPR gene-editing technologies to figure out what genes contribute to how mosquitoes are attracted to humans.[5] The goal is to use this knowledge to find new ways to use something more like a perfume and less like bug spray to help make humans "invisible" to mosquitoes. 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 and to continue to support the Centers of Excellence beyond 2021.

The services and funding provided by IMLS are critical in several areas—research infrastructure, workforce development and economic impact. The IMLS provides for the expansion of collections capabilities at American museums, which are key for the identification, documentation of locations, and classification of entomological species. Funding provides for the training and education of students and museum professionals. The 21st Century Museum Professionals Program provides opportunities for diverse and underrepresented populations to become museum professionals, expanding participation in an industry with an annual economic contribution of approximately $21 billion. Museums are critical to the public understanding of emerging major scientific issues through exhibits and programs, and in so doing, support science education as an integral part of the Nation's educational infrastructure. Finally, they make significant long-term contributions to economic development in their local communities, which is why the Society requests no less than $38.6 million for the Office of Museum Services within IMLS in fiscal year 2020.

ESA thanks the committee for the opportunity to provide input on these important priorities. ESA, headquartered in Annapolis, Maryland, is the largest organization in the world serving the professional and scientific needs of entomologists and

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[3] https://med.stanford.edu/news/all-news/2019/01/set-of-genes-predicts-severity-of-dengue.html.
[4] https://www.ncbi.nlm.nih.gov/pubmed/26518229.
[5] https://www.cell.com/action/showPdf?pii=S0960–9822%2819%2930215–5.

individuals in related disciplines. As the largest and one of the oldest insect science organizations in the world, ESA has over 7,000 members affiliated with educational institutions, health agencies, private industry, and government. Members are researchers, teachers, extension service personnel, administrators, marketing representatives, research technicians, consultants, students, pest management professionals, and hobbyists. For more information about the Entomological Society of America, please see http://www.entsoc.org/.

[This statement was submitted by Robert K.D. Peterson, PhD, President, Entomological Society of America.]

PREPARED STATEMENT OF THE EPILEPSY FOUNDATION

Dear Chairman Blunt and Ranking Member Murray:

The Epilepsy Foundation appreciates the opportunity to submit written testimony as the Subcommittee begins its work on the fiscal year 2020 Labor, Health and Human Services (HHS), Education and Related Agencies appropriations bill. The Epilepsy Foundation respectfully requests that the following funding levels be included in the final fiscal year 2020 Labor, HHS, Education and Related Agencies bill: $11.5 million for the Centers for Disease Control and Prevention (CDC)'s National Center for Chronic Disease Prevention and Health Promotion's Epilepsy program; $41.6 billion for the National Institutes of Health (NIH); $8.56 billion for the Health Resources & Services Administration's (HRSA) discretionary budget authority; and $46 million for the Agency for Healthcare Research and Quality (AHRQ). Our written testimony focuses on the incredible value and impact of CDC's Epilepsy program.

The Epilepsy Foundation is the leading national voluntary health organization that speaks on behalf of the approximately 3.4 million living with epilepsy and seizures. We foster the wellbeing of children and adults affected by seizures through research programs, educational activities, advocacy, and direct services. Epilepsy is a medical condition characterized by seizures, which are sudden surges of electrical activity in the brain, that affects a variety of mental and physical functions.

The Institute of Medicine's (IOM) report on epilepsy, Epilepsy Across the Spectrum: Promoting Health and Understanding, identifies the Epilepsy Foundation and the CDC leaders in addressing many of its national recommendations. The Epilepsy Foundation, supported by a cooperative agreement with CDC, has made the following progress:

—Provided education and/or direct training on epilepsy to more than 81,487 law enforcement and first responders, 57,511 school nurses and 407,649 students and teachers;
—Delivered evidence-based self-management training to people with epilepsy so that they can take control of their health, better cope with day-to-day challenges and reduce healthcare utilization and healthcare costs;
—Reached underserved populations through:
  —Project ECHO, a tele-mentoring process between an epilepsy specialist and primary care providers, in Ohio, Indiana, West Virginia and Kentucky;
  —An advanced practice provider model with family nurse practitioners and physician assistants;
  —Delivery of signature programs through local Epilepsy Foundation offices;
  —Training community health workers in Texas and Illinois; and
  —Outreach to behavioral health professionals in rural settings.

The Department of Health and Human Services initiative, Healthy People 2020, includes the goal to "increase the proportion of people with epilepsy and uncontrolled seizures who receive appropriate medical care." Continued and increased funding for the CDC epilepsy program is critical to meeting this goal—as it is the only public health program specifically related to epilepsy that offers a national scope and local community programs. Approximately 1 in 26 Americans will develop epilepsy at some point in their lifetime. There is no "one size fits all" treatment option for epilepsy, and despite available treatments, about a third of people living with epilepsy—approximately 1 million—suffer from uncontrolled or intractable seizures,[1] with many more living with significant side-effects. Among adults with epilepsy, only 50 percent have seen both a primary care physician and a neurologist and epilepsy specialist in the last year; 36 percent have seen a primary care physician only; 8 percent have seen a neurologist or epilepsy specialist only; and 6 per-

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[1] Patrick Kwan & Martin J. Brodie, Early identification of refractory epilepsy, 342 N ENGL J MED 314–9 (2000). Retrieved from https://www.nejm.org/doi/pdf/10.1056/NEJM200002033420503.

cent have seen neither.[2] Thirty-nine percent of those experiencing seizures in the last year have not seen a neurologist.[3] Compared to adults with no history of epilepsy, adults with active epilepsy are more likely to report not being able to afford their prescription drugs (21 percent v. 9 percent) and mental healthcare (8 percent v. 2 percent) when these were needed in the previous year.[4] Nine percent of those with active epilepsy report not being able to obtain needed healthcare because of a lack of transportation.[5]

In fiscal year 2019, $8.5 million was appropriated for the CDC's National Center for Chronic Disease Prevention and Health Promotion's Epilepsy program. The $3 million additional requested funds will help support epidemiologic studies, national dissemination of evidence-based programs to address the access of care barriers described above and expand provider education and public awareness campaigns to reduce stigma. Epilepsy accounts for $19.4 billion in direct costs (medical) and indirect costs (lost or reduced earnings and productivity) each year. To decrease this public health burden and help more people with epilepsy have a high quality of life and access the quality, physician-directed and person-centered healthcare they need, we simply must do more. The House Appropriations Committee has approved $11.5 million for the Epilepsy program in fiscal year 2020 and we urge the Senate to support $11.5 million in the final fiscal year 2020 LHHS appropriations bill.

If you have any questions, please contact the Epilepsy Foundation's Vice President of Government Relations and Advocacy Laura Weidner at lweidner@efa.org.

Sincerely.

[This statement was submitted by Philip M. Gattone, M.Ed., President & CEO and Laura Weidner, Esq., Vice President, Government Relations & Advocacy, Epilepsy Foundation.]

PREPARED STATEMENT OF THE FAMILY PLANNING COALITION

Chairman Blunt, Ranking Member Murray, and Subcommittee Members:

The undersigned organizations collectively represent millions of providers, patients, administrators, researchers, public health professionals, and advocates who support robust Federal funding of the Title X family planning program, which helps ensure that millions of individuals can obtain high-quality sexual and reproductive health services. We are deeply concerned by the administration's continued attacks on the integrity of the Title X program, as demonstrated by the devastating rule that the Department of Health and Human Services published March 4.[1] We urge the Senate to provide strong support for Title X's high-quality, evidence-based, and patient-centered care by adopting the House's appropriation of $400 million and language protecting the program's integrity in the fiscal year 2020 Labor, Health and Human Services, Education, and Related Agencies appropriations bill.

Title X helps more than 4 million people access family planning and related health services at nearly 4,000 health centers around the country annually.[2] More than 1.7 million of the people served are women of color.[3] For many individuals, particularly those who have low incomes, are under- or uninsured, or are adolescents, Title X-supported sites are their main access point to obtain affordable and confidential contraception, cancer screenings, sexually transmitted disease testing and treatment, complete and medically accurate information about their family planning options, and other basic care. In fact, a 2017 study found six in ten women seeking contraceptive services at a Title X health center saw no other healthcare providers that year.[4]

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[2] David J. Thurman et al., Health-care access among adults with epilepsy: The U.S. National Health Interview Survey, 2010 and 2013, 55 EPILEPSY BEHAV 184–88 (2015). Retrieved from https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5317396/.

[3] Ibid.

[4] Ibid.

[5] Ibid.

[1] Department of Health and Human Services. Final Rule. "Compliance with Statutory Program Integrity Requirements." Federal Register 84 (March 4, 2019): 7714–7791.

[2] Christina Fowler et al, "Family Planning Annual Report: 2017 National Summary," RTI International (August 2018). https://www.hhs.gov/opa/sites/default/files/title-x-fpar-2017-national-summary.pdf.

[3] Ibid. Calculations include the 642,470 white women who are Hispanic or Latina, 32,139 American Indian or Alaska Native women, 130,398 Asian women, 743,731 Black or African women, 28,652 Native Hawaiian or Pacific Islander women, and 127,378 multi-racial women.

[4] Mia Zolna, Megan Kavanaugh, and Kinsey Hasstedt. "Insurance-Related Practices at Title X-Funded Family Planning Centers under the Affordable Care Act: Survey and Interview Find-

Continued

The data shows that Title X makes a difference for patients. In 2015 alone, Title X-supported contraceptive services helped patients prevent an estimated 822,000 pregnancies.[5] In addition to clinical care, Title X supports important health center efforts that are not reimbursable under insurance, including staff training and community-based sexual and reproductive health education programs. Moreover, research has shown that Title X-supported services save the Federal and State governments approximately $7 billion a year,[6] and 76 percent of American adults, including 92 percent of Democrats, 52 percent of Republicans, and 80 percent of independents said in 2019 poll that it is important for the Federal Government to fund reproductive health services for women with lower incomes.[7]

In spite of the critical importance of equitable access to family planning services for all people, regardless of their income or insurance status, Title X remains woefully underfunded. In 2016, researchers from the Centers for Disease Control and Prevention, the Office of Population Affairs, and George Washington University estimated that Title X would need $737 million annually to deliver family planning care to all uninsured women with low incomes in the United States.[8] This estimate understates the true need for Title X, as it does not include an estimate of costs for men (who made up 12 percent of patients in the network in 2017),[9] gender non-binary persons, and the insured patients who rely on Title X's confidentiality protections.

The gap between the funds appropriated and the funds needed has only grown in recent years. From 2010 to 2014 the number of women estimated to be in need of publicly funded family planning services increased by one million,[10] but Congress cut Title X's funding by $31 million over that period. That decrease unfortunately corresponded to dramatic decreases in the number of patients served at Title X-funded sites; the numbers dropped from 5.22 million in 2010[11] to just over 4 million in 2017.[12]

This funding request comes in the wake of a final rule from the Trump-Pence administration that is unlawful, coercive, and dangerous for patients' health, including persons with low incomes, young people, people of color, LGBTQ people, and people experiencing intimate partner violence. On March 4, the administration published a final rule[13] that disregards medical ethics and evidence-based Federal guidelines in order to severely restrict the providers in the Title X network and the care that patients can receive from those remaining in the program. Federal judges in Washington, Oregon, and California swiftly issued preliminary injunctions against the rule in April 2019.[14] The undersigned organizations are firmly opposed to the illegal rule and urge Congress to protect the integrity of the program so that individuals can continue receive evidence-based care and Congress can powerfully demonstrate its support for the Title X program in its current form.

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ings." Guttmacher Institute (November 2017). https://www.guttmacher.org/article/2017/11/insurance-related-practices-title-x-funded-family-planning-centers-under-affordable.

[5] Jennifer Frost et al, "Publicly Funded Contraceptive Services at U.S. Clinics, 2015," Guttmacher Institute (April 2017). https://www.guttmacher.org/report/publicly-funded-contraceptive-services-us-clinics-2015.

[6] Adam Sonfield, "Beyond Preventing Unplanned Pregnancy: The Broader Benefits of Publicly Funded Family Planning Services," Guttmacher Policy Review (December 2014). https://www.guttmacher.org/gpr/2014/12/beyond-preventing-unplanned-pregnancy-broader-benefits-publicly-funded-family-planning.

[7] Ashley Kirzinger et al. KFF Poll: Public Opinion and Knowledge on Reproductive Health Policy. Kaiser Family Foundation (May 3, 2019). https://www.kff.org/womens-health-policy/poll-finding/kff-poll-public-opinion-and-knowledge-on-reproductive-health-policy/.

[8] Euna August, et al, "Projecting the Unmet Need and Costs for Contraception Services After the Affordable Care Act," American Journal of Public Health (February 2016): 334–341.

[9] Christina Fowler et al, "Family Planning Annual Report: 2017 National Summary," RTI International (August 2018). https://www.hhs.gov/opa/sites/default/files/title-x-fpar-2017-national-summary.pdf.

[10] Jennifer Frost, Lori Frohwirth and Mia Zolna, "Contraceptive Needs and Services, 2014 Update," Guttmacher Institute (September 2016). https://www.guttmacher.org/report/contraceptive-needs-and-services-2014-update.

[11] Christina Fowler et al, "Family Planning Annual Report: 2017 National Summary," RTI International (August 2018). https://www.hhs.gov/opa/sites/default/files/title-x-fpar-2017-national-summary.pdf.

[12] Fowler et al, "Family Planning Annual Report: 2016 National Summary."

[13] Department of Health and Human Services. Final Rule. "Compliance with Statutory Program Integrity Requirements." Federal Register 84 (March 4, 2019): 7714–7791

[14] See State of Washington v. Alex M. Azar II., No. 1:19-cv-03040–SAB (E.D. Wash. Apr. 25, 2019), American Medical Ass'n et al. v. Alex M. Azar II, et al., No. 6:19-cv-00317–MC (D. Or. Apr. 29, 2019), Essential Access Health, Inc. et al. v. Alex M. Azar, et al., No. 19-cv-01195–EMC (N.D. Cal. Apr. 26, 2019).

In April, the House Appropriations Committee recognized these challenges and acted to strengthen the Title X program by including an appropriation of $400 million and language to block the harmful Title X rule finalized in March and restore the full regulatory framework for Title X to its 2016 status. We urge you to adopt these critical provisions in your bill and maintain existing requirements that support the program's ability to fulfill Congress' vision for this essential public health program.

* * *

During the fiscal year 2020 appropriations process, Congress has the opportunity to stand against relentless attacks on family planning and support strong public funding for the Title X family planning network. The undersigned organizations urge you to begin the expansion of family planning and related healthcare services with this meaningful investment in, and protection for, Title X.

If you have any questions or would like additional information, please contact Lauren Weiss at the National Family Planning & Reproductive Health Association at lweiss@nfprha.org.

Thank you for considering these requests.

COG
Advocates for Youth
AIDS Action Baltimore
AIDS Alabama
AIDS Foundation of Chicago
Alliance for Justice
American Academy of Pediatrics
American Atheists
American Civil Liberties Union
American College of Nurse-Midwives
American Medical Student Association
American Psychological Association
American Public Health Association
American Sexual Health Association
American Society for Reproductive Medicine
Asian & Pacific Islander American Health Forum
Association of Maternal & Child Health Programs
Association of Women's Health, Obstetric and Neonatal Nurses
Black Women's Health Imperative
Cascade AIDS Project
Catholics for Choice
Center for Reproductive Rights
Endocrine Society
Equality California
Equality North Carolina
Equity Forward
Girls Inc.
Global Justice Center
Guttmacher Institute
Healthy Teen Network
HIV Medicine Association
Howard Brown Health
Human Rights Campaign
In Our Own Voice: National Black Women's Reproductive Justice Agenda
Jewish Women International
Medical Students for Choice
NARAL Pro-Choice America
NASTAD
National Abortion Federation
National Asian Pacific American Women's Forum (NAPAWF)
National Association of County and City Health Officials
National Association of Nurse Practitioners in Women's Health
National Council of Jewish Women
National Family Planning & Reproductive Health Association
National Hispanic Medical Association
National Institute for Reproductive Health (NIRH)
National Latina Institute for Reproductive Health
National LGBTQ Taskforce Action Fund
National Medical Association
National Network of Abortion Funds
National Organization for Women
National Partnership for Women & Families
National Women's Health Network
National Women's Law Center
NCSD
Nurses for Sexual and Reproductive Health
PAI
People For the American Way
Physicians for Reproductive Health
Planned Parenthood Federation of America
Population Connection Action Fund
Population Institute
Positive Women's Network—USA
Power to Decide
Reproductive Health Access Project
Ryan White Medical Providers Coalition
Sexuality Information and Education Council of the United States (SIECUS)
Silver State Equality
Society for Adolescent Health and Medicine
Society for Maternal-Fetal Medicine
The AIDS Institute
Treatment Action Group (TAG)
Union for Reform Judaism
URGE: Unite for Reproductive & Gender Equity
Women of Reform Judaism
YWCA USA

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 $41.6 billion in fiscal year 2020 for the National Institutes of Health (NIH) within the Department of Health and Human Services.

The National Institutes of Health (NIH) is the Nation's largest funder of biomedical research, providing competitive grants to more than 300,000 scientists working at universities, medical schools, independent research institutions, and companies across the country.

NIH is fueling new research breakthroughs that are transforming medicine. For example, a 2018 Nobel Prize recognized NIH-funded basic research that laid the foundation for cancer immunotherapy.[1] And new research may soon lead to more progress: a universal flu vaccine, a cure for sickle-cell disease, and new ways to combat the opioid epidemic.[2,3,4]

Innovations derived from basic biomedical research also lead to new companies and industries. The human genome project alone is estimated to have spurred nearly $1 trillion of economic activity.[5]

Congress's renewed commitment to NIH has enabled groundbreaking discoveries. But more work must be done to rebuild our Nation's research capacity; in real dollars, the NIH budget is approximately 9.5 percent below the fiscal year 2003 level (Figure 1).

Continued progress toward new cures and better therapies also requires strong support for early career scientists. The current funding environment makes it difficult for younger scientists to establish and maintain independent research careers, and to pursue innovative scientific directions.[6] Sufficient support is needed for these scientists who represent the future of biomedical research in the United States.

A $41.6 billion budget ($2.5 billion above fiscal year 2019) would allow NIH to accelerate progress in all areas of biomedical science and help train the next generation of scientists. This funding level could support about 400 additional young investigators; provide $500 million already authorized through the 21st Century Cures Act for key research initiatives; and bolster other areas in urgent need of additional resources, including investment in new research technologies such as cryogenic electron microscopy.

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[1] NIH grantee wins 2018 Nobel Prize in Physiology or Medicine, October, 2018.

[2] Universal Influenza Vaccine Research National Institute of Allergy and Infectious Disease, Bethesda, MD.

[3] NIH launches initiative to accelerate genetic therapies to cure sickle cell disease, September, 2018

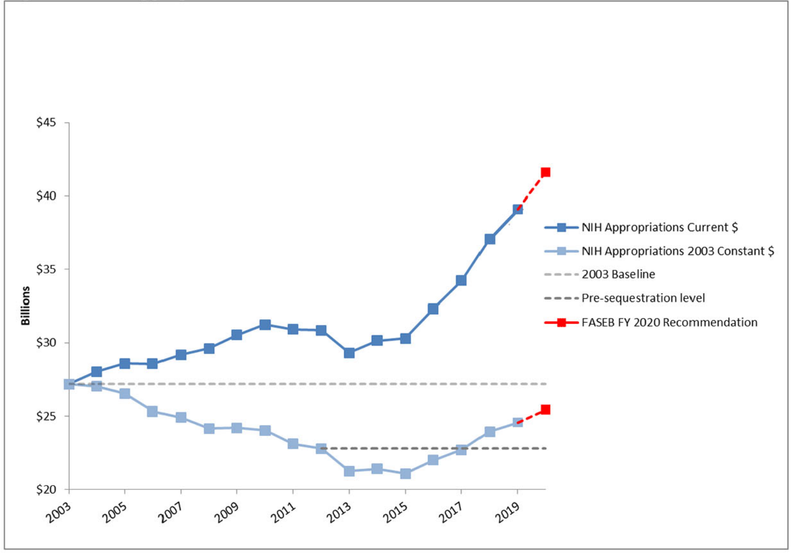
[4] NIH HEAL Initiative.

[5] Battelle/United for Medical Research. The impact of genomics on the U.S. economy, June 2013.

[6] Sustaining Discovery in the Biological and Biomedical Sciences: A Framework for Discussion. Federation of American Societies for Experimental Biology, Bethesda, MD.

FASEB FISCAL YEAR 2020 RECOMMENDATION: AT LEAST $41.6 BILLION FOR NIH

Figure 1: NIH Appropriations, FY 2003-2020



[This statement was submitted by Benjamin H. Krinsky, PhD, Associate Director for Legislative Affairs, Federation of American Societies for Experimental Biology.]

Prepared Statement of the Federation of Associations in Behavioral and Brain Sciences

The Federation of Associations in Behavioral and Brain Sciences (FABBS) represents 23 scientific societies and 58 university departments whose scientific members and faculty share a commitment to advancing knowledge in the sciences of mind, brain, and behavior. Understanding the human element of our most pressing challenges through research in these sciences have a potential to improve the health and education of our citizens. FABBS appreciates the opportunity to submit testimony in support of the Federal agencies investing in behavioral and cognitive science. For fiscal year 2020, FABBS encourages your subcommittee to provide the National Institutes of Health (NIH) with a budget of at least $41.6 billion, the National Center for Health Statistics (NCHS) within the Center for Disease Control a budget of at least $175 million, and the Institute of Education Sciences (IES), within the Department of Education a budget of $670 million.

FABBS would like to thank this subcommittee for the strong bipartisan vision and diligence last year. The community is extremely grateful that this subcommittee successfully completed a final Labor, Health and Human Services, Education budget for fiscal year 2019, sparing these agencies from experiencing an extended government shut down. We very much hope that we will see similar success funding these agencies for fiscal year 2020.

National Institutes of Health. We sincerely thank the Labor HHS Appropriations Subcommittee for its diligent work and considerable increases to NIH over the past 4 years. As members of the Ad Hoc Group for Medical Research and the Coalition for Health Funding, FABBS recommends at least $41.6 billion for NIH in fiscal year 2020. FABBS members contribute to the NIH mission of seeking fundamental knowledge about the behavior of living systems and the application of that knowledge to enhance health, lengthen life, and reduce illness and disability. The Office of Behavioral and Social Science Research (OBSSR) plays a particularly important role supporting the mission of NIH. OBSSR was created to coordinate and promote basic, clinical, and translational behavioral and social science research at the NIH. While the NIH budget has grown in recent years, funding for OBSSR has remained stagnant. We recognize that, located in the Office of the Director, OBSSR does not have a specific appropriation. Nonetheless, FABBS appreciates the opportunity to express support for OBSSR, underscore its key role supporting the mission of NIH, and raise concerns about recent flat funding.

Consistent with the Friends of the National Institute of Child Health and Human Development (NICHD), FABBS encourages the subcommittee to provide $1.6 billion to NICHD in fiscal year 2020, an increase of $94 million over fiscal year 2019. NICHD supports a range of research on behavior and child development, and has made important progress developing complex tools to measure children's cognitive, emotional, and social functioning. To build on these successes, additional funding for NICHD would enable more integrated behavioral and biobehavioral work on child developmental trajectories, across infancy, childhood, and adolescence, in both normative and at-risk environments, across diverse contexts (school, home, and community) and inclusive of underrepresented and vulnerable groups. Additional funding would also allow for more research on integrated behavioral health in primary care settings, including cost effectiveness comparisons, and impact of behavioral interventions on mental health, physical health, and quality of life.

National Center for Health Statistics, Center for Disease Control—As members of the Friends of NCHS, FABBS urges the Subcommittee to appropriate $175 million to NCHS in fiscal year 2020. We greatly appreciate the Subcommittee's longstanding support of NCHS and the data it produces on all aspects of our healthcare system, such as opioid and prescription drug use, healthcare disparities, and causes of death. Communities across the country rely on the high-quality data provided by NCHS to understand and improve health. With additional funding, NCHS could modernize surveys and data collection to produce information more quickly and efficiently, while reducing the reporting burden on local data providers.

Institute of Education Sciences, U.S. Department of Education—As members of the Friends of IES, FABBS encourages the subcommittee to appropriate at least $670 million to IES in fiscal year 2020. This funding level would restore IES to the fiscal year 2011 real dollar purchasing power level. IES is a semi-independent, nonpartisan branch of the U.S. Department of Education and is the research foundation for improving and evaluating teaching and learning. The four centers—the National Center for Education Statistics (NCES), National Center for Education Research (NCER), National Center for Special Education Research (NCSER) and National Center for Education Evaluation (NCEE)—work collaboratively to efficiently and comprehensively produce and disseminate rigorous research and high-quality data and statistics.

We recognize the pressing need to raise the budget caps. Accordingly, we have been working in collaboration with the broad scientific society, as well as with State and local colleagues, in health, education, and hundreds of other groups affected by non-defense discretionary funding, to encourage members of Congress to raise the caps so that we can complete the budget process, fund vital research, and keep our government working.

Thank you for the opportunity to express support for the following fiscal year 2020 budget requests:

—National Institutes of Health at least $41.6 billion
—National Center for Health Statistics at least $175 million
—Institute of Education Sciences at least $670 million

These investments to strengthen behavioral and cognitive research are critical to the health and education of our citizens. Thank you for considering this request.

FABBS Member Societies:

American Educational Research Association, American Psychological Association, Association for Applied Psychophysiology and Biofeedback, Association for Behavior Analysis, Behavior Genetics Association, Cognitive Science Society, International Society for Developmental Psychobiology, Massachusetts Neuropsychological Society, National Academy of Neuropsychology, The Psychonomic Society, Society for Behavioral Neuroendocrinology, Society for Computers in Psychology, Society for Judgement and Decision Making, Society for Mathematical Psychology, Society for Psychophysiological Research, Society for the Psychological Study of Social Issues, Society for Research in Child Development, Society for Research in Psychopathology, Society for the Scientific Study of Reading, Society for Text & Discourse, Society of Experimental Social Psychology, Society of Multivariate Experimental Psychology, Vision Sciences Society

FABBS Affiliates:

APA Division 1: The Society for General Psychology; APA Division 3: Experimental Psychology; APA Division 7: Development Psychology; APA Division 28: Psychopharmacology and Substance Abuse; Arizona State University; Binghamton

University—Psychology; Boston College- Psychology; Boston University—Psychology; California State University at Fullerton—Psychological and Brain Sciences; Carnegie Mellon University—Psychology; Cornell University—Psychology; Columbia University—Psychology; Duke University—Psychology and Neuroscience; Florida State University—Psychology; Georgetown University—Psychology; George Washington University—Psychology; Georgia Institute of Technology—Psychology; Harvard University—Psychology; Indiana University Bloomington—Psychology; Indiana University Purdue University Indianapolis—Psychology; Johns Hopkins University—Psychological and Brain Sciences; Kent State University—Psychological Sciences; Lehigh University—Psychology; New York University—Psychology; Northeastern University—Psychology; Northwestern University—Psychology; Ohio State University—Center for Cognitive and Brain Sciences; Pennsylvania State University—Psychology; Princeton University—Psychology; Purdue University—Psychological Sciences; Rice University—Psychology; Southern Methodist University—Psychology; Stanford University—Psychology; Syracuse University—Psychology; Temple University—Psychology; University of Arizona—Psychology; University of California at Berkeley—Psychology; University of California at Davis—Psychology; University of California at Los Angeles—Psychology; University of California at Riverside—Psychology; University of California at San Diego—Psychology; University of Chicago—Psychology; University of Cincinnati—Psychology; University of Delaware—Psychological & Brain Sciences; University of Houston—Psychology; University of Illinois at Urbana—Champaign—Psychology; University of Iowa—Psychological and Brain Sciences; University of Maryland at College Park—Psychology; University of Massachusetts at Amherst—Psychological and Brain Sciences; University of Michigan—Psychology; University of Minnesota—Psychology; University of Minnesota—Institute of Child Development; University of North Carolina at Greensboro—Psychology; University of Pennsylvania—Psychology University of Pittsburgh—Psychology; University of Texas at Austin—Psychology; University of Texas at Dallas—School of Behavioral and Brain Sciences; University of Virginia—Psychology; University of Washington—Psychology, Vanderbilt University—Psychological Sciences; Virginia Tech—Psychology; Wake Forest University—Psychology; Washington University in St. Louis—Psychology

[This statement was submitted by Juliane Baron, Executive Director, Federation of Associations in Behavioral and Brain Sciences.]

PREPARED STATEMENT OF THE FRED HUTCHINSON CANCER RESEARCH CENTER

Fred Hutchinson Cancer Research Center (Fred Hutch) is grateful to Congress for providing strong, reliable funding for the National Institutes of Health (NIH), a key national priority. The Nation's investment in NIH research pays a lifetime of dividends in better health and improved quality of life for all Americans. In fiscal year 2020, Fred Hutch recommends at least $41.6 billion for the NIH, including funds provided to the agency through the 21st Century Cures Act (Public Law 114–255) for targeted initiatives. These funding levels would continue the momentum of recent increases by enabling meaningful base budget growth above inflation, while ensuring the NIH Innovation Account created by the 21st Century Cures Act supplements the agency's base budget through dedicated funding for specific programs, as intended.

Through the strong, bipartisan action of this Subcommittee's leaders, Chairman Roy Blunt and Ranking Member Patty Murray, Congress is helping the agency regain lost ground after years of effectively flat budgets. In the fiscal year 2019 minibus bill, the Subcommittee's leadership ensured continued progress by providing a substantial increase to all NIH institutes and centers, in addition to dedicated funding through the 21st Century Cures Act and other funding devoted to specific priorities.

The Federal investment in biomedical research has yielded a significant number of scientific advances that help improve health outcomes for patients. NIH funding enables Fred Hutch to redefine what is possible across the full spectrum of biomedical research. Fred Hutch is committed to working with Congress and the Administration to further bipartisan support for increasing Federal investment in biomedical discovery and ensuring NIH remains a top priority in fiscal year 2020 and beyond.

ABOUT FRED HUTCH

Fred Hutch, founded in 1975, is designated by the National Cancer Institute (NCI) as a Comprehensive Cancer Center with the mission to eliminate cancer and related diseases as causes of human suffering and death. Fred Hutch's interdisciplinary team of world-renowned scientists and humanitarians work together to prevent, diagnose, and treat cancer, HIV/AIDS, and other diseases. Our Nobel Prize winning discoveries began in the 1970s with Dr. E. Donnall Thomas' work in bone marrow transplantation, providing the first definitive and reproducible example of the power of the human immune system's ability to cure cancer.

Today, Fred Hutch continues to pave the way in groundbreaking research to understand the fundamental biological mechanisms of cancers and infectious diseases, develop new methods of diagnosis and treatment, and generate new knowledge to help individuals and communities reduce the incidence and death rates from these causes of human suffering and death. Below are some examples of how NIH funding drives Fred Hutch innovation and accelerates research advancements in cancer and other diseases.

—*Advancing Next Generation Cancer Immunotherapy*.—Fred Hutch is paving the way for the next generation of immunotherapy treatments that harness the body's own immune system to fight cancer. Studies conducted by our scientists show these therapies can be more effective than conventional drugs, radiation, or surgery.

—*A New Path Toward a Cancer Vaccine*.—Fred Hutch researchers discovered the first human antibody against the Epstein-Barr virus, the first virus shown to cause cancer in humans. This discovery opens a new path toward a vaccine to block infection and potentially prevent about 200,000 cancer cases a year.

—*Discoveries in Women's Health*.—Launched in 1991 with a NIH grant, the Women's Health Initiative is one of the largest U.S. prevention studies of its kind and the largest, most ethnically and geographically diverse study of older women. A single study from the Women's Health Initiative, based at Fred Hutch, showing the health risks of combined hormone therapy led to tens of thousands fewer cases of breast cancer, heart disease and stroke, and venous thromboembolism between 2003 and 2012. This study generated a net return of $37.1 billion—roughly $140 on every dollar invested in the trial.

—*Milestones in Efforts Against HIV*.—Fred Hutch began its HIV research in 1988, and today leads the HIV Vaccine Trials Network (HVTN) supported by the National Institute of Allergy and Infectious Diseases (NIAID). HVTN is the world's largest publicly-funded international collaboration focused on the development of vaccines to prevent HIV/AIDS.

—*Breakthroughs in Cancer Prevention*.—Fred Hutch research extends to other infectious diseases, reflecting a growing understanding that eradicating certain infectious diseases can reduce the world's cancer burden. NCI-funded research at Fred Hutch showed strains of the human papillomavirus (HPV) cause nearly all cervical cancers. The team also found a way to produce virus-like particles that could trigger an immune response, paving the way for today's cancer-preventing HPV vaccines.

—*The Quest for a Universal Flu Vaccine*.—Scientists at Fred Hutch are studying the molecular evolution of the influenza virus from the virus' perspective to better understand how mutations allow it to escape the body's natural immune defenses and vaccination attempts. This basic understanding can be used to help inform future vaccine design.

—*Tracking Communicable Diseases in Real Time*.—To better understand the spread of infectious diseases, Fred Hutch scientists are sequencing data from pathogens, in real time, to form models that provide inferences that are actionable to public health. This approach is being used in viral systems such as influenza, ebola, zika, and measles.

—*Leveraging Data Science to Defeat Cancer*.—Fred Hutch is gathering vast amounts of data about health and disease, from DNA and RNA sequencing, to digital imaging. Our researchers are currently using the latest computational technologies to catalogue the working molecular components of cells that are involved in cancer and other life-threatening illnesses. Data about genes, proteins, and processes involved in cancer and the immune system can be searched for previously hidden patterns—clues that can lead to cures. With the right information about cancer biology and the right analytical tools, we can transform cancer prevention, diagnosis, and treatment.

THE VALUE OF FEDERALLY-FUNDED BIOMEDICAL RESEARCH

The Federal Government has an irreplaceable role in supporting biomedical research. No other public, corporate, or charitable entity is willing or able to provide broad and sustained funding for cutting-edge research necessary to yield new innovations and technologies of the future. The partnership between NIH and America's scientists and research institutions is a unique and highly-productive relationship that leverages the full strength of our Nation's research enterprise to foster discovery, improve our understanding of the underlying cause of disease, and develop the next generation of biomedical innovations—and innovators—that deliver better treatments and cures to patients.

As an independent research institute with its sole mission to pursue lifesaving discoveries, Fred Hutch depends on NIH funding to focus on basic, translational, clinical, public health, and infectious disease research, and to respond quickly to the research needs of the country. In addition to supporting robust funding, Fred Hutch opposes provisions—such as directives to reduce the salary limit for extramural researchers—which would harm the integrity of the research enterprise and disproportionately affect independent research institutes. Policies to cut salary support hinder the center's research mission and ability to recruit and retain the talented researchers who make U.S. institutions global leaders in advancing the biomedical sciences and improving and saving lives.

The NIH initiatives focusing on career development and recruitment of a diverse scientific workforce are important to innovation in biomedical research and public health. Robust increases to the NIH budget are critical to fostering the next generation of scientists, as training funds work to attract the brightest minds to pursue a career in research. Fred Hutch is committed to training the current and next generation of scientific leaders from diverse backgrounds and supports NIH efforts to address challenges faced by investigators seeking to launch and sustain their research careers.

CONCLUSION

Fred Hutch thanks the Subcommittee for its important work dedicated to ensuring the health of the Nation and for its strong support for NIH funding in fiscal year 2019. We appreciate the opportunity to urge the Subcommittee to provide at least $41.6 billion in fiscal year 2020 for NIH, including funds provided to the agency through the 21st Century Cures Act for targeted initiatives, which is the next step toward a multi-year increase in our Nation's investment in biomedical research. Advances in bioscience, technology, and data science have brought us to an inflection point. This is not a time to pull back. Given the abundance of scientific opportunity, this recommendation represents a minimum investment to sustain progress that only would be amplified through an even more robust commitment.

[This statement was submitted by Gary Gilliland, MD, PhD, President and Director, Fred Hutchinson Cancer Research Center.]

PREPARED STATEMENT OF THE FRIENDS OF THE NATIONAL INSTITUTE ON DRUG ABUSE

Thank you for the opportunity to submit testimony in support of the National Institute on Drug Abuse (NIDA). The Friends of the National Institute on Drug Abuse is a coalition working with about 150 scholarly organizations with a total membership of at least 2 million scholars, clinicians and educators who are committed to eliminating drug abuse in society. Realizing the very limited support for research in this area from either philanthropy or industry causes us to realize that over 80 percent of all research in this area must come from NIDA. We coordinate the opinions of the participating organizations, who also actively participate on their own to provide important information to policy makers to make decisions that will lead to the elimination of this disease which now is killing so many of our citizens. Clearly research has proven to be important in this area. For example, former research which led to the creation of drugs such as naloxone and buprenorphine has provided important mechanisms which have prevented the death rate from being even much higher. Clearly the investment in research has paid off for so many families. We need more research in all areas of basic and clinical science to make additional advances.

In the fiscal year 2020 Labor-HHS Appropriations bill, we request that the subcommittee provide at least $2.5 billion above the fiscal year 2019 level for the National Institutes of Health (NIH), and within that amount a proportionate increase for the National Institute on Drug Abuse (NIDA) using the Institute's conferenced level of $1,419,844,000 as NIDA's base budget for Fiscal 2020. In addition, within the NIH total, we request at least $500 million for targeted research on opioid misuse and addiction, development of opioid alternatives, pain management, and addiction treatment, of which at least $250 million is allocated to NIDA and included in its base budget for Fiscal 2020. We also respectfully request the inclusion of the following NIDA specific report language.

Opioid Initiative. The Committee continues to be extremely concerned about the epidemic of prescription opioids, heroin, and illicit synthetic opioid use, addiction and overdose in the U.S. Approximately 174 people die each day in this country from drug overdose (over 100 of those are directly from opioids), making it one of the most common causes of non-disease-related deaths for adolescents and young adults. This crisis has been exacerbated by the availability of illicit fentanyl and its analogs in many communities. The Committee appreciates the important role that research plays in the various Federal initiatives aimed at this crisis. To combat this crisis, the bill includes at least $250,000,000 for research related to preventing and treating opioid misuse and addiction. With additional funding for NIDA targeted at addressing the opioid epidemic, the Institute's opioid specific allocation should be targeted for the following areas: development of safe and effective medications and new formulations and combinations to treat opioid use disorders and to prevent and reverse overdose; conduct demonstration studies to create a comprehensive care model in communities nationwide to prevent opioid misuse, expand treatment capacity, enhance access to overdose reversal medications, and enhance prescriber practice; test interventions in justice system settings to expand the uptake of medication assisted treatment and methods to scale up these interventions for population-based impact; and develop evidence-based strategies to integrate screening and treatment for opioid use disorders in emergency department and primary care settings.

Addressing the Opioid Crisis in Rural Regions. The Committee encourages NIDA to continue its partnership with the CDC, SAMHSA, and the Appalachian Regional Commission in support of research to help communities develop comprehensive approaches to prevent and treat consequences of opioid injection, including substance use disorders, overdose, HIV, hepatitis B and C virus infections, as well as sexually transmitted diseases. These projects will serve as models for addressing opioid injection epidemics that can be implemented by health systems in similar rural communities in the U.S.

Raising Awareness and Engaging the Medical Community in Drug Abuse and Addiction Prevention and Treatment. Education is a critical component of any effort to curb drug use and addiction, and it must target every segment of society, including healthcare providers (doctors, nurses, dentists, and pharmacists), patients, and families. Medical professionals must be in the forefront of efforts to curb the opioid crisis. The Committee continues to be pleased with the NIDAMED initiative, targeting physicians-in-training, including medical students and resident physicians in primary care specialties (e.g., internal medicine, family practice, and pediatrics). NIDA should continue its efforts in this space, providing physicians and other medical professionals with the tools and skills needed to incorporate substance use and misuse screening and treatment into their clinical practices.

Marijuana Research. The Committee is concerned that marijuana public policies in the States (medical marijuana, recreational use, etc.) are being changed without the benefit of scientific research to help guide those decisions. NIDA is encouraged to continue supporting a full range of research on the health effects of marijuana and its components, including research to understand how marijuana policies affect public health.

The HEALthy Brain and Child Development (BCD) Study. The Committee recognizes and supports the NIH HEALthy Brain and Child Development Study, which will establish a large cohort of pregnant women from regions of the country significantly affected by the opioid crisis and follow them and their children for at least 10 years. This knowledge will be critical to help predict and prevent some of the known impacts of pre- and postnatal exposure to drugs or adverse environments, including risk for future substance use, mental disorders, and other behavioral and developmental problems. The Committee recognizes that the BCD Study is supported in part by the NIH HEAL Initiative?, and encourages other NIH Institutes, such as NICHD, NIMH, NHLBI, NCI, NIAAA, NIMH, NINR, as well as the Office of the Director to support this important study.

Electronic Cigarettes. The Committee understands that electronic cigarettes (e-cigarettes) and other vaporizing equipment are increasingly popular among adolescents, and requests that NIDA fund research on the use and consequences of these devices. The Committee also supports the Population Assessment of Tobacco and Health (PATH) Study, a collaboration between NIDA and the U.S. Food and Drug Administration (FDA) Center for Tobacco Products to help scientists learn how and why people start using tobacco products, quit using them, and start using them again after they have quit, as well as how different tobacco products affect health outcomes over time.

Barriers to Research. The Committee is concerned that restrictions associated with Schedule I of the Controlled Substance Act effectively limit the amount and type of research that can be conducted on certain Schedule I drugs, especially marijuana or its component chemicals and new synthetic drugs and analogs. At a time when we need as much information as possible about these drugs to find antidotes for their harmful effects, we should be lowering regulatory and other barriers to conducting this research. The Committee directs NIDA to provide a short report on the barriers to research that result from the classification of drugs and compounds as Schedule I substances.

Drug abuse is costly to Americans; it ruins lives, while tearing at the fabric of our society and taking a financial toll on our resources. Over the past three decades, NIDA-supported research has revolutionized our understanding of addiction as a chronic, often-relapsing brain disease -this new knowledge has helped to correctly emphasize the fact that drug addiction is a serious public health issue that demands strategic solutions.

NIDA supports a comprehensive research portfolio that spans the continuum of basic neuroscience, behavior and genetics research through medications development and applied health services research and epidemiology. While supporting research on the positive effects of evidence-based prevention and treatment approaches, NIDA also recognizes the need to keep pace with emerging problems. We have seen encouraging trends in strategies to address these problems, but areas of continuing significant concern include the recent increase in lethalities due to heroin and synthetic fentanyl, as well as continued abuse of prescription opioids. Our knowledge of how drugs work in the brain, their health consequences, how to treat people already addicted, and what constitutes effective prevention strategies has increased dramatically due to research. However, since the number of individuals who are affected is still rising, we need to continue the work until this disease is both prevented and eliminated from society.

We understand that the fiscal year 2020 budget cycle will involve setting priorities and accepting compromise, however, in the current climate we believe a focus on substance abuse and addiction deserves to be prioritized accordingly. Thank you for your support for the National Institute on Drug Abuse.

PREPARED STATEMENT OF THE FRIENDS OF THE HEALTH RESOURCES AND SERVICES ADMINISTRATION COALITION

The Friends of HRSA coalition is a nonpartisan coalition of nearly 170 national organizations representing tens of millions of public health and healthcare professionals, academicians and consumers invested in the Health Resources and Services Administration's mission to improve health outcomes and achieve health equity. We are pleased to submit our request of $8.56 billion for the Health Resources and Services Administration in fiscal year 2020. We strongly urge you to reject the many proposed cuts to important HRSA programs contained in the president's fiscal year 2020 budget proposal.

HRSA's 90-plus programs and more than 3,000 grantees support tens of millions of geographically isolated, economically or medically vulnerable people, in every State and U.S. territory, to achieve improved health outcomes by increasing access to quality healthcare and services; fostering a healthcare workforce able to address current and emerging needs; enhance population health and address health disparities through community partnerships; and promote transparency and accountability within the healthcare system. The agency is a national leader in improving the health of Americans by addressing the supply, distribution and diversity of health professionals and supporting training in contemporary practices, and providing high-quality health services to populations who may otherwise not have access to healthcare.

HRSA programs work in coordination with each other to maximize resources and leverage efficiencies. For example, Area Health Education Centers, a health professions training program, was originally authorized at the same time as the National Health Service Corps to increase the number of primary care providers at health centers and other direct providers of healthcare services for underserved areas and populations. AHECs play an integral role to recruit providers into primary healthcareers, diversify the workforce and develop a passion among future providers for service to the Nation's underserved communities.

HRSA's programs also work in collaboration across the Federal Government to enhance health outcomes. For example, HRSA's HIV/AIDS Bureau partners with the Office of the Assistant Secretary for Health, the Centers for Disease Control and Preventions, the Substance Abuse and Mental Health Services Administration, the

Centers for Medicare and Medicaid Services, the Indian Health Services, the National Institutes of Health, the Agency for Healthcare Research and Quality, the Department of House and Urban Development, the Department of Veterans Affairs and the Department of Justice to ensure an effective use of resources, and a coordinated and focused public health response to the HIV epidemic. This Federal response has contributed to the number of annual HIV infections dropping 18 percent since 2008, with HRSA's Ryan White HIV/AIDS Program serving as the foundation for delivering healthcare and support services to reach the public health goal of ending the HIV epidemic. Despite this success, an estimated 1.1 million people in the U.S. are living with HIV today, and nearly 40,000 become newly infected every year—1 in 7 of whom are unaware of their infection. HRSA programs will play an integral role in achieving the public health goal of ending the HIV epidemic.

HRSA grantees also play an active role in addressing emerging health challenges. For example, HRSA's grantees provide outreach, education, prevention, screening and treatment services for populations affected by health emergencies such as the opioid epidemic. However, much of this work required additional funding to increase capacity in health centers, support National Health Service Corps providers to deliver relevant care and expand rural health services. Strong, sustained funding would allow HRSA to quickly and effectively respond to emerging and unanticipated future health needs across the U.S., while continuing to address persistent health challenges.

HRSA programs and grantees are providing innovative and successful solutions to some of the Nation's greatest healthcare challenges including the rise in maternal mortality, the severe shortage of health professionals, the high cost of healthcare, and behavioral health issues related to substance use disorder—including opioid misuse. We are grateful for the increases provided for HRSA programs in fiscal year 2019, however HRSA's discretionary budget authority remains nearly 20 percent below the fiscal year 2010 level (adjusted for inflation). We recommend Congress build upon the important increases they provided for HRSA programs in fiscal year 2019 and provide $8.56 billion for HRSA's total discretionary budget authority in fiscal year 2020. Additional funding will allow HRSA to pave the way for new achievements and continue supporting critical HRSA programs, including:

—Primary care programs support more than 11,000 health center sites in every State and territory, improving access to preventive and primary care for more than 28 million people in geographic areas with few healthcare providers. Health centers coordinate a full spectrum of health services including medical, dental, vision, behavioral and social services in the Nation's most underserved communities. Health centers reach 1 in 3 people living at or below the Federal poverty line; 1 in 5 rural residents; 1 in 5 uninsured persons; and 1 in 6 Medicaid beneficiaries.

—Health workforce programs support the education, training, scholarship and loan repayment of primary care physicians, nurses, oral health professionals, optometrists, physician assistants, nurse practitioners, clinical nurse specialists, public health personnel, mental and behavioral health professionals, pharmacists and other allied health providers. With an emphasis on primary care and training in interdisciplinary, community-based settings, these are the only Federal programs focused on filling the gaps in the supply of health professionals, as well as improving the geographic distribution and diversity of the workforce.

—Maternal and child health programs, including the Title V Maternal and Child Health Block Grant, Healthy Start and others, support initiatives designed to promote optimal health, reduce disparities, combat infant and maternal mortality, prevent chronic conditions and improve access to quality healthcare for mothers and babies. MCH programs help assure that nearly all babies born in the U.S. are screened for a range of serious genetic or metabolic diseases, and that coordinated long-term follow-up is available for babies with a positive screen. They also help improve early identification and coordination of care for children with sensory disorders, autism and other developmental disabilities. The MCH Block Grants funded 59 States and jurisdictions to provide healthcare and public health services for an estimated 56 million people, reaching 86 percent of pregnant women, 99 percent of infants, and 55 percent of children nationwide.

—HIV/AIDS programs provide the largest source of Federal discretionary funding assistance to States and communities most severely affected by HIV/AIDS. The Ryan White HIV/AIDS Program delivers comprehensive care, prescription drug assistance, and support services to 550,000 people impacted by HIV/AIDS. HRSA's Ryan White HIV/AIDS Program effectively engages clients in comprehensive care and treatment, including increasing access to HIV medication, which has resulted in 86 percent of clients achieving viral suppression, compared to just 59 percent of all people living with HIV nationwide. Additionally, the program provides education and training for health professionals treating people with HIV/AIDS, and works toward addressing the disproportionate impact of HIV/AIDS on racial and ethnic minorities.

—Title X ensures access to a broad range of reproductive, sexual and related preventive health services for more than 4 million women, men and adolescents, with priority given to low-income individuals. Services include patient education and counseling for family planning; provision of contraceptive methods; cervical and breast cancer screenings; sexually transmitted disease prevention education, testing and referral; and pregnancy diagnosis. This program helps improve maternal and child health outcomes and promotes healthy families.

—Rural health programs improve access to care for people living in rural areas. The Office of Rural Health Policy serves as the Nation's primary advisor on rural policy issues, conducts and oversees research on rural health issues and administers grants to support healthcare delivery in rural communities. Rural health programs are designed to support community-based disease prevention and health promotion projects, help rural hospitals and clinics implement new technologies and strategies and build health system capacity in rural and frontier areas.

—Special programs include the Organ Procurement and Transplantation Network, the National Marrow Donor Program, the C.W. Bill Young Cell Transplantation Program and National Cord Blood Inventory. These programs maintain and facilitate organ marrow and cord blood donation, transplantation and research, along with efforts to promote awareness and increase organ donation rates. Special programs also include the Poison Control Program, the Nation's primary defense against injury and death from poisoning for over 50 years. Poison control centers contribute to significantly decreasing a patient's length of stay in a hospital and save the Federal Government $662.8 billion each year in medical costs and lost productivity.

Our recommendation is based on the need to continue improving the health of Americans and to provide HRSA with the resources needed to pave the way for new achievements. We urge you to consider HRSA's central role in strengthening the Nation's health and advise you to adopt our fiscal year 2020 request of $8.56 billion for HRSA's discretionary budget authority. Thank you for the opportunity to submit our recommendation to the subcommittee.

[This statement was submitted by Gaby Witte, Senior Manager of Government Relations, American Public Health Association.]

PREPARED STATEMENT OF THE FRIENDS OF THE INSTITUTE OF EDUCATION SCIENCES

Chairman Blunt, Ranking Member Murray, and Members of the Subcommittee; thank you for the opportunity to submit written testimony on behalf of the Friends of IES, a consortium of scientific and professional societies, research universities, and independent research organizations interested in supporting the mission of IES and the use of research and statistics. We urge you to include $670 million for the Institute of Education Sciences (IES) in the fiscal year 2020 Labor, Health and Human Services, and Education Appropriations bill.

IES is the independent and nonpartisan statistics, research, and evaluation arm of the U.S. Department of Education charged with supporting and disseminating rigorous scientific evidence on which to ground education policy and practice. As such, it serves as the critical Federal source for funding groundbreaking research in myriad aspects of teaching and learning, as well as rigorous analysis of educational programs and initiatives.

Its four centers—the National Center for Education Statistics (NCES), National Center for Education Research (NCER), National Center for Special Education Research (NCSER) and National Center for Education Evaluation (NCEE)—work collaboratively to efficiently and comprehensively deliver rigorous research and high-quality data and statistics. This information is essential to address our Nation's most pressing educational challenges and to help States and districts build a culture of evidence-driven policy.

Our member organizations rely on IES to support vital research that probes many of the most important questions confronting American education—from literacy and numeracy at the elementary level, to the integration of technology in teaching and learning, to advancing STEM education, to closing achievement gaps at every level of our educational systems. Yet, only one of every ten grant proposals receives funding support, limiting the ability of IES to support emerging lines of inquiry and tackle pressing questions about education, such as what can be done to increase school safety, address challenges facing rural districts, support improved teacher professional development and supports, and bolster the impact of technology in the classroom.

The National Center for Education Statistics (NCES) compiles and disseminates important, scientifically valid data on the condition of education that is essential to the research being conducted across the Nation. NCES also provides the funding support and infrastructure for the State Longitudinal Data Systems, which have helped States link K–12, postsecondary, and workforce systems to gain a better understanding of education and workforce outcomes and serve as the basis of tools such as early warning systems that identify students at risk of dropping out of school.

The Regional Educational Laboratories (RELs) conduct applied research that is directly relevant to State and district administrators, principals and teachers. RELs also ensure that research is shared widely through its deep dissemination networks. Recent work across the REL network has focused on literacy, including the development of a rubric for evaluating reading/language arts instructional materials for kindergarten to grade 5; a self-study guide for implementing early literacy interventions; and a study on time to language proficiency for Hispanic English learner students. With additional resources the RELs could produce additional research-based materials so that educators may better serve these incredibly diverse regions. Moreover, IES helps inform policymakers, practitioners, and State and local governments about the most effective strategies, interventions, curricula and teacher training, through the What Works Clearinghouse powered by IES.

The National Center for Special Education Research (NCSER) is the only Federal agency specifically designated to develop and provide evaluations for programs for students with disabilities. Research funded by NCSER includes the development and evaluation of positive behavior supports strategies, programs to support students who experience reading difficulties, and interventions to foster self-determination in students with disabilities as they transition into adulthood. With a budget that is only two-thirds of the amount appropriated in 2005, NCSER has been unable to fund critical topics such as special education teacher quality and shortages, high leverage practices, and potential linkages between students with disabilities and enrollment in developmental education classes in higher education.

Public education expenditures generally account for a significant share of State and local budgets. As States continue to implement the Every Student Succeeds Act (ESSA)'s provisions to promote evidence-based, innovative educational practices, it is more important than ever for the Federal Government to provide robust funding to the agency charged with compiling and disseminating evidence-based educational research and data. The Foundations for Evidence-based Policymaking Act also calls for the Federal Government to leverage statistical information and rigorous evaluations for informing policy.

To this end, we urge the Committee to support funding IES at $670 million in fiscal year 2020. A commitment at this level will enable IES to more fully support research that addresses the challenges of preparing young Americans to succeed in the knowledge-based economy that is not only upon us now, but also is the key to future American prosperity.

[This statement was submitted by Felice J. Levine, Chair, Friends of the Institute of Education Sciences.]

PREPARED STATEMENT OF THE FRIENDS OF THE NATIONAL CENTER FOR HEALTH STATISTICS

As Chair of the Friends of the National Center for Health Statistics (Friends of NCHS), I am pleased to offer this written testimony for inclusion in the official committee record. We urge the Subcommittee to appropriate $175 million in fiscal year 2020 for the National Center for Health Statistics (NCHS) within the Centers for Disease Control and Prevention (CDC).

The Friends of NCHS is a coalition representing over 60 scientific, public health, and research organizations, all of whom rely on the information produced by the National Center for Health Statistics. We greatly appreciate the Subcommittee's longstanding support of NCHS and the data it produces on all aspects of our healthcare system, including opioid and prescription drug use, maternal and infant mortality, chronic disease prevalence, healthcare disparities, emergency room use, health insurance coverage, teen pregnancy, and causes of death.

As a result of the rising costs of conducting surveys and years of flat or near-flat funding, NCHS has had to focus nearly all of its resources on continuing to produce the high-quality data that communities across the country depend on to understand their health. However, NCHS is also facing an increasingly urgent need to respond to rising costs, declining response rates, and an ever-more complex healthcare system. This can only be achieved through investing in much-needed innovation and modernization that would allow it to produce better information more quickly and efficiently, while reducing the reporting burden on local data providers. With additional funding, NCHS could capitalize on opportunities surrounding advances in statistical methodology, big data, and computing by:

—Linking data reporting systems and better integrating electronic health records into NCHS' data production, allowing it to receive and process information more efficiently, reduce burden on data providers, and analyze and release statistics faster;

—Researching how to conduct its most complex surveys more efficiently, making surveys less costly to taxpayers and less burdensome on participants; and

—Integrating machine learning into its analysis to spot trends in Americans' health earlier.

Thank you for the opportunity to present this testimony on behalf of the Friends of NCHS. Please do not hesitate to contact me should you require additional information.

[This statement was submitted by Julia Milton, Chair, Friends of the National Center for Health Statistics and Director of Public Affairs, Consortium of Social Science Associations.]

PREPARED STATEMENT OF THE FRIENDS OF THE NATIONAL INSTITUTE ON AGING

Chairman Blunt, Ranking Member Murray, and Members of the Senate Labor, Health and Human Services, and Education, and Related Agencies Appropriations Subcommittee, I am Jennifer Pharaoh, chair of the Friends of the National Institute on Aging (FoNIA). FoNIA is grateful for your continued commitment to the mission of National Institutes of Health (NIH), and, in particular, the research supported and conducted by the National Institute on Aging (NIA). As you prepare the fiscal year 2020 appropriations legislation, we respectfully request at least $41.6 billion in funding for the NIH. Within this amount, we request that an increase of $500 million over fiscal year 2019 levels be designated in support of cross-Institute aging research initiatives. In addition, the FONIA requests an increase of at least $350 million above the final enacted amount for fiscal year 2019 for AD/ADRD research at the NIH.

The FoNIA is a coalition of more than 50 academic, patient-centered and non-profit research and aging organizations supporting NIA's mission to understand the nature of aging and the aging process, and diseases and conditions associated with growing older in order to extend the healthy, active years of life.

With the unprecedented growth in the Nation's aging population, there is a critical need for robust and sustained Federal investment in aging research spanning the spectrum of discovery, including research that builds on the basic science of aging as well as translational research and clinical application. The numbers illustrate the need: it is projected that, by 2030, more than 74 million Americans will be 65 or older—more than twice the number in 2000—and representing nearly 21 percent of the total U.S. population. In addition, the number of adults age 85 or older is expected to triple between 2010 and 2050.

As growing numbers of Americans live well into their 80s, aging-related diseases and multiple chronic conditions will become an even larger public health concern. Advancing age is the most important risk factor for many serious diseases and conditions including Alzheimer's disease and related forms of dementia (AD/ADRD), diabetes, many types of heart disease, cancers, osteoporosis and kidney failure.

The NIA sponsors and conducts the lion's share of Federal aging research that contributes significantly to the improved care and quality of life of older adults. A key NIA priority is to translate research into better and more efficient care through the development of effective interventions that are disseminated to healthcare providers, patients and caregivers. Transformational tools, including technological innovations, advance the effective prevention, early detection, diagnosis and treatment of disease that will help reduce the burden of illness for older adults and their families.

Such meaningful increases in NIH funding are essential to advancing research needed to make progress in addressing chronic disease, AD/ADRD, and other diseases and conditions that disproportionately affect older adults. For example, the sustained and robust Federal investment in AD/ADRD research, as supported by the Subcommittee in recent years, is making it possible for the NIA to continue with the acceleration of ground-breaking research while building an infrastructure to further expand the NIA's research footprint in the field.

In addition, NIA plays an instrumental role in facilitating and supporting aging-related research undertaken by other Institutes. Several NIA research projects and initiatives are highlighted below:

Health and Retirement Study. The NIA Division of Behavioral and Social Research supports the Health and Retirement Study, the Nation's premier source of combined data on health and socioeconomic status of adults over the age of 50. The data is used to calculate life expectancy and the costs of age-related conditions and diseases.

Diagnostics. Intramural researchers at the National Institute of Allergy and Infectious Diseases (NIAID) developed a new ultrasensitive test to detect tau protein associated with AD and chronic traumatic encephalopathy (CTE). This new test, adapted from a diagnostic test originally developed for prion diseases, could be a major advancement for AD research, diagnostics, and therapy development. The work, published in Acta Neuropathologica, was partially supported by the NIA.

Mitochondria and Inflammation. An international team of scientists led by investigators from the NIA Intramural Research Program have narrowed in on a potential new treatment target for Alzheimer's disease involving mitochondria, the powerhouses of the cell.

GeroScience Interest Group. The NIA established of the trans-NIH GeroScience Interest Group (GSIG) to advance initiatives to facilitate discovery on the common risks and mechanisms behind age-related diseases. Most NIH Institutes participate in the GSIG, which has held two summits; a third summit is planned in 2019.

Blood Pressure Control and Mild Cognitive Impairment. In a jointly funded project from several NIH Institutes, the Systolic Blood Pressure Intervention Trial (SPRINT) Memory and Cognition in Decreased Hypertension (SPRINT MIND) trial showed the impact of intensive management of systolic blood pressure on the reduction in the occurrence of mild cognitive impairment for participants in the intensive treatment group. These findings, published in the Journal of the American Medical Association, suggest encouraging effects of blood pressure management on cognition.

NIA is at the forefront of discovering and applying scientific advancements to enhance the health of older adults, lengthen life, and reduce illness and disability. In fact, to further its work in ensuring representation of older adults in representative research, the NIH implemented a new guideline on the inclusion of individuals across the lifespan. The ongoing efforts to revisit and revise the NIH-wide inclusion policy, as mandated in the 21st Century Cures Act passed in 2016, were discussed in a Viewpoint Essay published in the Journal of the American Medical Association in October 2018.

With millions of older Americans facing the loss of their functional abilities, their independence and their lives to chronic diseases and conditions of aging, the FoNIA respectfully requests your continued support for the vital work of the NIA. The FoNIA looks forward to working with you to secure the necessary resources for the ground-breaking aging research at the NIA, and across other NIH Institutes.

Respectfully Submitted.

[This statement was submitted by Jennifer Pharaoh, Chair, 2018–2019, Friends of the National Institute on Aging.]

PREPARED STATEMENT OF FSH SOCIETY

Honorable Chairman Blunt, Ranking Member Murray, and distinguished members of the Subcommittee, thank you for the opportunity to testify.

Facioscapulohumeral Disease (FSHD) is a heritable disease and one of the most common neuromuscular disorders with a prevalence of 1:8,000.[1] It affects 934,000 children and adults of both sexes worldwide. FSHD is characterized by progressive loss of muscle strength that is asymmetric and widely variable. Muscle weakness typically starts at the face, shoulder girdle and upper arms, often progressing to the legs, torso and other muscles. In addition to affecting muscle it can bring with it breathing issues, hearing loss, eye problems and cardiac arrhythmias. FSHD causes significant disability and death.

FSHD is associated with epigenetic changes at chromosome 4q35 in the D4Z4 DNA macrosatellite repeat array region leading to an inappropriate gain of expres-

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sion (function) of the D4Z4-embedded double homeobox 4 (DUX4) gene.[2] DUX4 is a transcription factor that kick starts the embryonic genome during the 2- to 8-cell stage of development.[3,4,5] Ectopic expression of DUX4 in skeletal muscle leads to muscle death. DUX4 is never expressed in 'healthy' muscle. FSHD has had few clinical trials,[6,7,8,9,10] and currently there is no cure or therapeutic option available to patients. DUX4 requires and needs to activate its direct transcriptional targets for DUX4-induced gene aberration and muscle toxicity.[11,12,13,14,15,16,17,18,19,20,21,22,23,24] Blocking DUX4's ability to activate its targets has profound therapeutic relevance.[25]

NIH-supported basic research on muscle disease and muscular dystrophy over the past 25 years has improved health outcomes. Small molecule and genetically engineered therapies are now in the works for FSHD and on the market for several neu-

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romuscular diseases![26,27,28,29,30,31,32] Each year, the non-profit, private and public investment in research yields critical advances in FSHD. Together we foster new treatments, diagnostics, and intervention strategies that affect the health of our Nation. Meticulous efforts by FSHD researchers/clinicians working with funding from FSH Society, the NIH and others have brought forth significant advancements in epigenetic diseases. FSHD is the only human disease known to be caused by the contraction of repetitive "junk" DNA. The Society has funded approximately $11 million in seed grants for research.

Let me now turn your attention to how together we can contain healthcare costs and improve outcomes via three initiatives: the FSH Society Industry Collaborative Workshop (hereafter called 'FSHS NIH/FDA Collaborative'), the NIH supported FSH Society annual International Research Congress (hereafter called 'FSHS NIH IRC') and the NIH Action Plan for the Muscular Dystrophies (hereafter called 'DHHS NIH MD Plan') (See https://mdcc.nih.gov/Action__Plan).

On March 12, 2019, in Silver Spring, the FSHS NIH/FDA Collaborative assembled 10 academic thought leaders, 17 industry representatives (8 companies), 5 NIH officers and scientists (EP/IP: NCATS, NIAMS, NINDS), 6 FDA scientists and regulators (CDER, CBER, DNP), and 9 patient advocates and organizations to discuss clinical trial readiness and accelerated approval process for therapies. We assessed disease tractability in four directions: natural history,[33,34] pharmacodynamic bio-

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markers,[35,36] imaging biomarkers,[37,38,39] and clinical trial design/readiness.[40,41,42] A journal publication/manuscript (in process) will detail roadblocks that need rapid mitigation in seven areas: diagnostics, molecular biomarkers, imaging biomarkers, functional outcome measures, patient reported outcomes, biorepository and animal models.

In June 2018, over 135 researchers from around the world gathered at the FSHS NIH IRC meeting, co-funded by the U.S. DHHS NIH, in Las Vegas to present the latest data and discuss research strategies. The FSHD scientific community listed 2019–2020 priorities as:

Table II. 2019 IRC Research Priorities (Source: https://www.fshsociety.org/events/international-research-conference/for full version)

1. Therapeutics

Therapeutics Trial Toolkit, including biological biomarkers, imaging markers, and clinical outcome assessments; Non-DUX4-centric therapies that ameliorate some of the major pathological drivers in FSHD, and/or augment muscle repair;

2. Pathophysiology

Pathophysiology, such as the role of DUX4 in fibrosis, inflammatory infiltrates, and fatty infiltration; temporal analysis of disease models; and novel model systems;

3. Molecular Mechanisms

Molecular mechanisms of DUX4 pathology and function;

4. Genetics and Epigenetics

Genetics and epigenetics around harmonizing diagnostics, disease continuum and genotyping, and understanding genetic modifiers and drivers of genetic variability.

Last, but not least, this Subcommittee and Congress in partnership with NIH, patients and scientists have made truly outstanding progress in understanding and treating the nine major types of muscular dystrophy through the Muscular Dystrophy Community Assistance, Research and Education Amendments of 2001 (MD–CARE Act, Public Law 107–84). The Federal advisory committee mandated by MD CARE Act, called the MDCC, along with working groups of outside scientific experts in the field assembled the '2015 NIH Action Plan for the Muscular Dystrophies.' It was presented by the Director of NIH to Congress. It specifies 81 objectives, in six sections (mechanism, screening, treatments, trial readiness, access to care, infrastructure including workforce) in need of funding and further development.[43] The genetics that give rise to FSHD are so remarkable, NIH Director Dr. Francis Collins emphasized its significance on the front page of the New York Times, saying "If we

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were thinking of a collection of the genome's greatest hits, this [FSHD] would go on the list."[44] We understand this Subcommittee seeks evidence of translating research spending into tangible improvement in health status and patient care. The FSHS NIH/FDA Collaborative, 'FSHS NIH IRC' and the 'DHHS NIH MD Plan' demonstrate the solid gains and show the rate of change in care.

Honorable Chairman, these advances in scientific understanding and epidemiological surveillance come at a significant cost. Since passing the MD CARE Act in 2001, NIH funding for FSHD has been unbalanced given the growth in discoveries and needs to be set right.

FSHD RESEARCH DOLLARS & FSHD AS A PERCENTAGE OF TOTAL NIH MUSCULAR DYSTROPHY FUNDING

[Dollars in millions]

Fiscal Year	2007	2008	2009	2010	2011	2012	2013	2014	2015	2016	2017	2018	2019
All MD ($ millions) ...	$47.2	$56	$83	$86	$75	$75	$76	$78	$77	$79	$81	$85ea	$80e
FSHD ($ millions)	$3	$3	$5	$6	$6	$5	$5	$7	$8	$9	$12.8	$13.7a	$17a
FSHD (percent total MD)	5%	5%	6%	7%	8%	7%	7%	9%	10%	11%	16%	16%	21%

Sources: NIH/OD Budget Office & NIH OCPL & NIH RePORT RCDC (e=estimate, a=actual)

The NIH is the principal worldwide source of funding of research on FSHD. Currently active projects are $17.037 million fiscal year 2019 (actual), a portion of the estimated $80 million spent on all muscular dystrophies. fiscal year 2019 projects cover 1 F31, 1 K22, 1 K23, 13 R01, 1 R13, 4 R21, 1 P01, 4 P50, 3 U01, 1 ZIC grants. There are 30 active projects NIH-wide totaling $17.037 million as of March 21, 2019, versus 28 active projects NIH-wide totaling $13.654 million as of April 18, 2018; and 28 active projects NIH-wide totaling $12.751 million as of March 3, 2017. (source: NIH Research Portfolio Online Reporting Tools (RePORT) keyword 'FSHD or facioscapulohumeral or landouzy-dejerine').

Without research on muscle disease, supported by the FSHD patient-advocacy groups in concert with the NIH biomedical research funding—families with FSHD would be living shorter, less productive, and far less hopeful lives. Nearly 41,000 Americans have FSHD, a disease that can cause damage to skeletal muscle, hearing, vision, breathing and lead to death.

What we need. Viewing at the current portfolio alongside the areas in need of bolstering in FSHD the NIH needs to fast expand its portfolio. Specifically, NIH needs to increase funding by adding R01 and R21 style grants in areas outlined by hundreds of experts in the FSHS NIH/FDA Collaborative, the FSHS NIH IRC and the DHHS NIH MD Plan. The engine of Federal research runs on the basic building blocks of workforce training, exploratory/developmental research grants (parent R21) and research project grants (parent R01). NIH can issue targeted funding announcements covering FSHD. A request for applications (RFA) on FSHD will yield results. These efforts will help convey to FSHD patients and allied researchers that NIH encourages more grant applications coming through its front door.

We request for fiscal year 2020, a doubling of the NIH FSHD research portfolio to $40 million. We are very appreciative of the slow but steady year-to-year increases and thank NIH and Congress. At this moment in time, FSHD needs an infusion of NIH grants both submitted and funded—investments in centers, collaborative research grants—and, most importantly, a rapid ramp up of basic/exploratory, preclinical and therapeutic research awards along with moderate expansion of postdoctoral and clinical training fellowships. FSHD research calls for and needs this additional funding in order to succeed. Honrable Chairman, thank you again for your help and efforts.

[This statement was submitted by Daniel Paul Perez, Co-founder, FSH Society.]

PREPARED STATEMENT OF THE GBS|CIDP Foundation International

SUMMARY OF RECOMMENDATIONS FOR FISCAL YEAR 2020

—Provide $41.6 billion for the National Institutes of Health (NIH) and proportional increases across its Institutes and Centers

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- Continue expanding GBS research supported by NIH with proportional funding increases for the National Institute of Neurological Disorders and Stroke (NINDS), and the National Institute of Allergy and Infectious Diseases (NIAID)

Chairman Blunt, Ranking Member Murray and distinguished members of the Subcommittee, thank you for your time and your consideration of the priorities of the community of individuals impacted by Guillain-Barré Syndrome (GBS), Chronic Inflammatory Demyelinating Polyneuropathy (CIDP), and related conditions as you work to craft the fiscal year 2020 L–HHS Appropriations Bill.

ABOUT GBS, CIDP, VARIANTS, AND RELATED CONDITIONS

Guillain-Barré Syndrome

Guillain-Barré Syndrome (GBS) is an inflammatory disorder of the peripheral nerves outside the brain and spinal cord. GBS is characterized by the rapid onset of numbness, weakness, and often paralysis of the legs, arms, breathing muscles, and face. Paralysis is ascending, meaning that it travels up the limbs from fingers and toes towards the torso. Loss of reflexes, such as the knee jerk, are usually found. Usually, a new case of GBS is admitted to ICU (Intensive Care) to monitor breathing and other body functions until the disease is stabilized. Plasma exchange (a blood “cleansing” procedure) and high dose intravenous immune globulins are often helpful to shorten the course of GBS. The acute phase of GBS typically varies in length from a few days to months. Patient care involves the coordinated efforts of a team such as a neurologist, physiatrist (rehabilitation physician), internist, family physician, physical therapist, occupational therapist, social worker, nurse, and psychologist or psychiatrist. Recovery may occur over 6 months to 2 years or longer. A particularly frustrating consequence of GBS is long-term recurrences of fatigue and/or exhaustion as well as abnormal sensations including pain and muscle aches.

CHRONIC INFLAMMATORY DEMYELINATING POLYNEUROPATHY

CIDP is a rare disorder of the peripheral nerves characterized by gradually increasing weakness of the legs and, to a lesser extent, the arms. It is the gradual onset as well as the chronic nature of CIDP that differentiates it from GBS. Like GBS, CIDP is caused by damage to the covering of the nerves, called myelin. It can start at any age and in both genders. Weakness occurs over two or more months. Unlike GBS, CIDP is chronic, with symptoms constantly waxing and waning. Left untreated, 30 percent of CIDP patients will progress to wheelchair dependence. Early recognition and treatment can avoid a significant amount of disability.

Post-treatment life depends on whether the disease was caught early enough to benefit from treatment options. The gradual onset of CIDP can delay diagnosis by several months or even years, resulting in significant nerve damage that may take several courses of treatment before benefits are seen. The chronic nature of CIDP differentiates long-term care from GBS patients. Adjustments inside the home may need to be made to facilitate a return to normal life.

ABOUT THE FOUNDATION

The Foundation’s vision is that every person afflicted with GBS, CIDP, or variants has convenient access to early and accurate diagnosis, appropriate and affordable treatments, and dependable support services.

The Foundation’s mission is to improve the quality of life for individuals and families across America affected by GBS, CIDP, and their variants by:

- Providing a network for all patients, their caregivers and families so that GBS or CIDP patients can depend on the Foundation for support, and reliable up-to-date information.
- Providing public and professional educational programs worldwide designed to heighten awareness and improve the understanding and treatment of GBS, CIDP and variants.
- Expanding the Foundation’s role in sponsoring research and engaging in patient advocacy.

CENTERS FOR DISEASE CONTROL AND PREVENTION

CDC and the National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP) have resources that could be brought to bear to improve public awareness and recognition of CIDP and related conditions. In order to initiate new, potentially cost-saving programs, CDC requires meaningful funding increases to support crucial activities. CIDP is a progressive condition in which patients can end up almost completely paralyzed and on a ventilator. The key to limiting serious health impacts is an early and accurate diagnosis. The time it takes for a CIDP patient to begin therapy is linked to the seriousness of the health impacts. An early diagnosis can mean the difference between a brief or extended hospital stay. For the Federal healthcare system, there is an economic incentive to ensure early and accurate diagnosis as longer hospitalizations equate to higher costs.

NATIONAL INSTITUTES OF HEALTH

NIH hosts a modest research portfolio focused on GBS, CIDP, variants, and related conditions. This research has led to important scientific breakthroughs and is well positioned to vastly improve our understanding of the mechanism behind these conditions. We ask that resources continue to be used to support a State of the Science Conference between NIAID, NINDS and the GBS|CIDP community. This conference would allow intramural and extramural researchers to develop a roadmap that would lead research into these conditions into the next decade, and encourage younger investigators to apply for grants that lead to sustained research activities. We are continuing to have conversations with the leadership of both institutes to facilitate a robust agenda and list of goals for the Conference. In our meetings with the leadership, we also spoke about the possibilities of cross-institute work between NINDS and NIAID to expand the research and understanding of the link between Zika and GBS. While such a conference would not require additional appropriations, the Foundation urges you to provide NIH with meaningful funding increases to facilitate growth in the GBS, CIDP, and related conditions research portfolio.

PATIENT ACCESS

As we have seen from communities that currently have access to home infusion, such as primary immunodeficiency diseases, the ability to choose the home as the preferred site of care has tremendous benefit in terms of health outcomes and overall convenience for patients. Individuals with CIDP and MMN often face mobility issues as limbs suffer nerve damage. Traveling to receive an infusion presents a tremendous hardship to many patients and their families. This hardship greatly affects rural patients who have to travel hundreds of miles to major cities in order to receive treatment, which can be both inconvenient and costly. The Foundation has seen that when there are obstacles to receiving regular infusions, patients tend to skip scheduled infusions, which leads to progressive disability. Many CIDP and MMN patients have access to IVIG home infusion through private insurance, which allows them to lead productive and active lives. When these individuals age on to Medicare, they can face disruption in their routine and suboptimal circumstances when managing their condition. Further, because the body's immune system is depressed at the end of an infusion cycle, CIDP and MMN patients face an elevated risk of contracting illness from visiting well-traveled sites of care for infusions. Most importantly, patients and physicians should have the authority to choose their preferred site of care. We hope that members of this subcommittee and Congress as a whole support legislation that will grant our patients this important access.

Patient Perspective

The Foundation was founded nearly 40 years ago, and the four pillars that guide our mission are: support, education, advocacy, and research. Our patients rely on the premier research that is carried out at the NIH to improve the diagnosis and treatment process of these devastating illnesses. Without appropriate funding to the NIH and CDC, my fear as a parent of a GBS survivor and the Executive Director of the Foundation, is that many patients will needlessly suffer. There is so much to learn; there is no bio-marker and we do not know why the immune system reacts to trigger these conditions. I ask the Committee to provide $41.6 billion to the NIH with proportional increases to NIAID and NINDS to continue the potentially life-saving work being done for our community, and ask for Congressional support of our initiative to improve access to life-saving treatments.

[This statement was submitted by Lisa Butler, Executive Director, GBS|CIDP Foundation International.]

PREPARED STATEMENT OF GERIATRICS WORKFORCE ENHANCEMENT PROGRAM AND THE GERIATRIC ACADEMIC CAREER AWARD PROGRAM

As the Co-Project Directors of the Gateway Geriatric Workforce Enhancement Program at Saint Louis University School of Medicine, we are pleased to submit this joint statement for the record recommending appropriations of at least $51 million in fiscal year 2019 to support geriatrics workforce training under the Geriatrics Workforce Enhancement Program (GWEP) and the Geriatric Academic Career Award (GACA) program administered by the Health Resources and Services Administration (HRSA). We thank you for your past support.

The most resent Notice of Funding Opportunity (NOFO) for geriatrics will fund 47 GWEP sites and one of their primary responsibilities is to educate primary care providers in caring for older adults. Unfortunately, each GWEP will receive about $100,000 less for their programs than the first round of grants provided in 2015. Our funding request would allow for additional GWEP sites in rural and underserved communities and for supplemental payments for GWEPs that provide additional training for caregivers, including family caregivers. This request would also include at least the cost of the recent NOFO for 26 GACA Program awards. These two geriatrics programs were funded at $40.7 million in fiscal year 2019.

In fiscal year 2015, HRSA combined the geriatric education programs in Titles VII and VIII of the Public Health Service Act, including the Geriatric Academic Career Award, as well as portions of the Alzheimer's Disease Prevention, Education, and Outreach Program to establish the Geriatrics Workforce Enhancement Program (GWEP). The GWEP is now the only Federal program designed to develop a healthcare workforce specifically trained to care for the complex health needs of older Americans with the most effective and efficient methods, providing higher quality care and saving valuable resources by reducing unnecessary costs. As you are aware, the number of Americans ages 65 and older will double from 46 million today to over 98 million by 2060, creating an imperative for policymakers to enhance the education of health professionals to improve care of older persons and, thus decrease costs of care.

Proven results from activities under the GWEP and its predecessor programs include an important increase in the number of teaching faculty with geriatrics expertise in a variety of disciplines, plus thousands of healthcare providers and family caregivers better prepared to support older Americans with complex chronic conditions. We recognize that the Subcommittee faces complex decisions in a constrained budget environment, but we believe a top priority should be a commitment to geriatric education programs that help the Nation's health workforce better serve the rapidly increasing number of older persons.

The Nation faces a shortage of geriatrics health professionals and direct service workers. There are not enough geriatricians, advanced practice nurses, and other health professionals with the knowledge, skills, and training in geriatrics to meet the needs of our rapidly growing population of older adults and to support their family caregivers. Too often, the result is expensive walk-in care and inappropriate return to hospital within thirty days of discharge. We believe that funding for GWEP-based geriatric education supports a sustainable future for the Nation's healthcare and Social Security systems by ensuring that (a) healthcare specialists trained in geriatric care do not become an expensive resource from which only a select few are able to benefit and (b) direct service workers and family caregivers are prepared to support a lower cost, independent lifestyle for community residing elders.

In recent years, GWEPs have continued the impressive work of the Geriatric Education Centers. Approximately half of the GWEPs provide education for areas that are more than 50 percent rural. In the 2017–2018 academic year, GWEPs provided gerontological education to more than 49,000 fellows and students. Continuing education for the current workforce is another critical part of the program's success with 212,444 faculty and practicing professionals participated in 1,564 unique continuing education courses offered by GWEP grantees during this period. Saint Louis University and other GWEPs are partnering with federally Qualified Health Centers to provide geriatric primary care education and didactic training. GWEPs create opportunities for healthcare providers in underserved and remote areas of the country to consult with top experts in geriatric care through Interactive Televideo (ITV), interactive teleconsults, and synchronous webcasts, and make available thousands of hours of online geriatric education programs.

The Gateway Geriatric Education Center at Saint Louis University has provided education to 25,611 health professionals and 5,904 members of the public since 2016. These health professionals have provided screenings for geriatric problems such as frailty, sarcopenia (muscle weakness), falls, and dementia to 9,280 older adults in all six Congressional districts in Missouri. More than 80 percent of this trainings and evaluation of older persons were in primary care settings and medically underserved communities. Developed specifically for the GWEP, the Rapid Geriatric Assessment has been computerized in multiple health systems, including Perry County Memorial Hospital in Perryville, Missouri, a critical access hospital in rural Perry County, and CARESTLHealth, a federally Qualified Health Center in north St. Louis city, Missouri. In Perry County, over 25 percent of the older adults in the county have been screened using this assessment process. Our screenings thus far, have identified 25.4 percent with dementia and 31.9 percent with falls. Early intervention for these conditions can decrease medical costs. Upon identifying concerns in any of the assessment areas, older patients are referred for other GWEP-initiated services, to include: Cognitive Stimulation Therapy—a non-pharmacologic intervention for persons with dementia or Exercise and Strengthening programming. In addition, our GWEP has provided education through in-person and on-line continuing education, through daily tweets on Twitter (@meddocslu)—828, to date—and with 102 postings to LinkedIn and Facebook. Our GWEP also co-produced a regional prime time television program on aging which was viewed by 340,739 persons. The YouTube site has had 103,200 views.

Highlights from other GWEPS include:

—The Dartmouth GWEP is disseminating education across the Nation in the highly successful Geriatric Interdisciplinary Team Training program.

—The South Central Foundation GWEP is providing support for improving home-based care for the native community throughout the State Alaska.

—In rural eastern North Carolina, the East Carolina University GWEP is disseminating training on caring for older members of the farming, fishing, and lumber industries.

These are some of the highlights of the contributions made by only four GWEPs. Obviously, the GWEPs are playing a major role in improving healthcare for older adults in the United States. Multiply this by 44 (the number of existing GWEPs) and you can begin to visualize the scope and impact of this program across the Nation. It is important to note that every GWEP is focused on meeting the needs of rural and/or underserved populations; many serve predominantly people of color and those who are economically challenged.

GWEP awardees have received expanded authorization to provide family caregivers and direct service workers with instruction on prominent issues in the care of older adults, such as Alzheimer's Disease and other dementias, palliative care, self-care, chronic disease self-management, falls, and maintaining independence, among others. In Missouri, we have developed Cognitive Stimulation Therapy (CST) aimed at enhancing functioning in persons with moderate Alzheimer's disease. We have trained over 1200 persons to deliver this intervention and this has led to over 500 persons with dementia participating in this effective intervention which our research has shown to improve cognition. Our GWEP has recently been designated by the founders of CST as the North American CST Training Center.

HRSA estimates that 52,352 paid and family caregivers will participate in GWEP training programs over the current grant period. For example, the GWEP at Saint Louis University is partnering with several Area Agencies on Aging, the local Alzheimer's Association, a rural hospital, a rural osteopathic school, the regional Area Health Education Centers, and dementia-focused community care agencies to train staff and family caregivers in assessing and supporting them through the caregiving process. The 2016 National Academies of Sciences, Engineering, and Medicine (NASEM) report Families Caring for an Aging America acknowledged that training must go beyond the healthcare professions and support family caregivers. This will improve the quality of health outcomes while saving valuable resources in the healthcare system.

In summary, GWEPs have improved the supply, distribution, diversity, capabilities, and quality of healthcare professionals who care for our Nation's growing older adult population, including the underserved and minorities. They train physicians, nurses, social workers, dentists, mental health professionals, pharmacists, and caregivers. In some States, the GWEP is offering training to first responders to keep elders safe in their communities. Some of the professionals trained through GWEPs will become academicians in geriatric medicine, dentistry, psychiatry, nursing, and allied health professions, thereby giving additional cohorts of professionals the skills they need to properly serve older Americans. Furthermore, GWEPs create and deliver community-based programs that provide patients, families, and caregivers with the skills to care for older adults and improve health outcomes, including Alzheimer's disease education. The GWEPs are serving as change agents and helping to transform a fragmented and outmoded system.

We ask for your continued support for geriatric programs to adequately prepare the next generation of health professionals and care providers for the rapidly changing and emerging needs of the growing and aging population.

On behalf of NAGE and those who have benefitted in Missouri and from our colleagues around the country, thank you for your thoughtful consideration of our request for funding for GWEPs and GACAs in fiscal year 2019. NAGE is a non-profit membership organization representing GWEPs, Geriatric Education Centers, Centers on Aging, and other programs that provide education and training to healthcare professionals and others in geriatrics and gerontology.

[This statement was submitted by John E. Morley, MB, BCh, and Marla Berg-Weger, PhD., LCSW, Co-Project Director, Gateway Geriatric Workforce Enhancement Program.]

PREPARED STATEMENT OF THE GLOBAL HEALTH COUNCIL

Global Health Council (GHC), the leading alliance of non-profits, businesses, and universities, dedicated to saving lives and improving the health of people worldwide, thanks the Subcommittee for the opportunity to submit this testimony in support for the Center for Global Health within the Centers for Disease Control and Prevention (CDC).

The recent Ebola outbreaks in West Africa and Zika highlighted the important work that the Center for Global Health (CGH) at CDC does to protect the health of millions around the world, but also Americans here at home. Every year, CGH is on the frontlines of investigating and responding to disease outbreaks. To that end, Global Health Council recommends at a minimum fiscal year 2019 funding levels for CGH but recognizes that $642 million is needed to ensure CGH has the needed resources to address current and future public health threats. In addition, Global Health Council recommends $208 million for CGH's Division of Global Health Protection, which implements global health security programs at CDC.

CDC serves a critical role in gathering and sharing public health data and evidence, and one of its greatest assets is the level of expertise it brings to both the domestic and global health spheres. In the area of global health, CDC leads efforts in global disease surveillance, capacity building, and research in the development of new health technologies and tools. Its work has resulted in significant advances against a number of diseases, including the eradication of smallpox.

The Center for Global Health protects the health of Americans by monitoring 24/7 disease outbreaks around the world. CGH works in over 60 countries and partners with ministries of health, international organizations, and other global health partners not only to monitor and control disease outbreaks, but also to foster local ownership and strengthen countries' capacity to prevent, detect, and respond to such events.

In addition, CGH is home to the Global HIV/AIDS, Global Immunization, Parasitic Disease and Malaria, and Global Public Health Capacity Development programs. These programs position CGH as a leader in global immunization, disease eradication, and public health capacity building, and are critical to CDC's global health mission. Through these programs, CGH works to strengthen foreign government's research and laboratory infrastructure, train new health professionals, foster resilient health systems equipped with clean water and sanitation facilities, and conduct research to develop new technologies to combat diseases around the world.

The Division of Global Health Protection within CGH leads the administration's engagement on the Global Health Security Agenda (GHSA), an international initiative to help countries build their capacities to detect and respond to infectious disease outbreaks. In this effort, CDC collaborates with national governments, international organizations, and civil society to prevent and reduce the likelihood of disease outbreaks, detect potential and emerging threats, and coordinate a rapid, effective response. With funding from the Emergency Ebola Supplemental, which has bolstered funding for these activities, set to expire at the end of fiscal year 2019, it is critical that the annual appropriations for the Division of Global Health Protection is increased to ensure this work continues.

Since the 2014 Ebola outbreak in West Africa, CDC has invested in training epidemiologists, upgrading laboratories, and stockpiling drugs and equipment. These investments have helped countries like Liberia (ground-zero for Ebola in 2014) respond to an outbreak in less than 24 hours, as opposed to 90 days. Cameroon has shortened its response time to cholera outbreaks from 8 weeks to just 24 hours. The ongoing Ebola crisis in the Democratic Republic of the Congo (DRC), now the second largest outbreak in history, demonstrates the importance of continued funding for global health security activities. Making investments today in building capacity helps to contain and halt outbreaks at their origin, preventing an outbreak from becoming a global pandemic, thus reducing the funding needed for an emergency response.

Funding for CGH ensures that we have the right tools, infrastructure, staff, and systems in place to prevent future outbreaks from spiraling out of control, and we cannot afford to retreat on these investments. Sustained funding will ensure that

CGH continues to build strong health systems that ensure security and improvement of health of those around the world, as well as Americans.

We encourage you to maintain robust investments in global health programs at CDC, while also maintaining funding for other critical humanitarian and development programs that enable the United States to reach its goal of ending extreme poverty and creating a more stable, prosperous world.

Global Health Council thanks the Subcommittee for the opportunity to submit written testimony in support of the Center for Global Health at CDC. 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

On behalf of the Global Health Technologies Coalition (GHTC), a group of more than 30 nonprofit organizations, academic institutions, and aligned businesses advancing policies to accelerate the creation of new drugs, vaccines, diagnostics, and other tools that bring healthy lives within reach for all people, I am providing testimony on fiscal year 2020 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 long-standing and emerging health challenges.

To achieve this goal, we respectfully request maintaining robust funding for NIH, particularly the National Institute for Allergy and Infectious Diseases and the Fogarty International Center, providing funding to match CDC's increased responsibilities in global health and global health security—at minimum, funding of $513.62 million for the CDC Center for Global Health (CGH) and $644.62 million for the CDC National Center for Emerging Zoonotic and Infectious Diseases (NCEZID), in line with the House bill—and supporting funding for BARDA's critical work in emerging infectious diseases.

We also strongly urge the Subcommittee to continue its established support for global health R&D by urging leaders at the NIH, CDC, the Food and Drug Administration, and other entities within the U.S. Department of Health and Human Services, like the Office of Global Affairs, BARDA, and the NIH Fogarty International Center, to join leaders of other U.S. agencies to develop a cross-government global health R&D strategy to ensure that U.S. investments in global health research are efficient, coordinated, and streamlined.

GHTC members strongly believe that sustainable investment in R&D for a broad range of neglected diseases and health conditions is critical to tackling both long-standing and emerging global health challenges that impact people around the world and in the United States. My testimony reflects the needs expressed by our members, which work with a wide variety of partners in nearly one hundred countries to develop new and improved technologies for the world's most pressing health issues.

Critical Need For New Global Health Tools.—While we have made tremendous gains in global health over the past fifteen years, millions of people around the world are still threatened by HIV/AIDS, tuberculosis (TB), malaria, and other neglected diseases and conditions. In 2107, TB killed 1.3 million people, surpassing deaths from HIV/AIDS. 1.8 million people were newly diagnosed with HIV. Nearly half of the global population remains at risk for malaria and drug resistant strains are growing. Maternal mortality is 19 times greater in under-resourced regions than developed countries. One out of every 13 children in Sub-Saharan Africa dies before the age of 5, often from vaccine-preventable and other communicable diseases. These figures highlight the tremendous global health challenges that remain and the need for sustained investment in global health R&D to deliver new tools to combat endemic and emerging threats.

New tools and technologies are critical, both to address unmet global health needs and address challenges of drug resistance, outdated and toxic treatments, and difficulty administering current health technologies in poor, remote, and unstable settings. As seen with recent outbreaks of Ebola and Zika, we simply do not have all the tools needed to prevent, diagnose, and treat many neglected diseases—yet the emerging evidence of the impact of an experimental Ebola vaccine candidate currently being deployed in the epidemic in the Democratic Republic of the Congo, developed in part with funding from the U.S. Government, demonstrates the power of having the right tool at the right time to respond to a health emergency. It is critical to invest in the development of next generation tools to fight existing and emerging disease threats and have tools ready to go when we need them.

RESEARCH AND U.S. GLOBAL HEALTH EFFORTS

The United States is at the forefront of innovation in global health, with NIH, CDC, and BARDA leading much of our global health research.

NIH.—The groundbreaking science conducted at the NIH has long upheld U.S. leadership in medical research. Within the NIH, the National Institute of Allergy and Infectious Diseases, the Office of AIDS Research, and the Fogarty International Center all play critical roles in developing new health technologies that save lives at home and around the world. Recent activities have led to the creation of new tools to combat neglected diseases, including vaccines for dengue and trachoma, new drugs to treat malaria and TB, and multiple projects to develop diagnostics, vaccines, and treatments for Ebola—including supporting clinical trials for the rVSV–ZEBOV investigational Ebola vaccine currently being deployed to counter the Ebola epidemic in the Democratic Republic of the Congo. Leadership at NIH has long recognized the vital role the agency plays in global health R&D and has named global health as one of the agency's top five priorities.

We recognize and are grateful for Congress' work to bolster funding for NIH, including through the 21st Century Cures Act. It remains critical that support for NIH considers all pressing areas of research—including research in neglected diseases. To deliver on the remarkable progress being made across the institutes, it is vital that we renew our commitment to health research and maintain steady support for the NIH.

CDC.—The CDC also makes significant contributions to global health research, particularly through CGH and NCEZID. CDC's ability to respond to disease outbreaks, like recent episodes of Zika and Ebola, is essential to protecting the health of citizens both at home and abroad, and the work of its scientists is vital to advancing the development of tools, technologies, and techniques to detect, prevent, and respond to urgent public health threats. Important work at NCEZID includes the development of innovative technologies to provide a rapid diagnostic test for the Ebola virus, a new vaccine to improve rabies control, and a new and more accurate diagnostic test for dengue virus. The center also plays a leading role in the National Strategy for Combating Antibiotic-Resistant Bacteria, to prevent, detect, and control outbreaks of antibiotic resistant pathogens, such as drug-resistant TB.

Programs at CDC's CGH—including the Global HIV/AIDS, Global Immunization, Parasitic Diseases and Malaria, Global Disease Detection and Emergency Response, and Global Public Health Capacity Development programs—have also yielded tremendous results in the development and refinement of vaccines, drugs, microbicides, and other tools to combat HIV/AIDS, TB, malaria, and neglected tropical diseases like leishmaniasis and dengue fever. In addition, the CGH plays a critical role in disease detection and response, working to monitor and respond to outbreaks, develop new tools to help detection efforts, train epidemiologists in high-burden regions, and build capacity of health systems.

As global disease outbreaks have grown in frequency and intensity, CDC's work in novel technology development and global health security has only become more important. This includes the agency's efforts in the Democratic Republic of Congo to quash that country's tenth outbreak of Ebola, now the second largest Ebola outbreak in history, as well as CDC's engagement with the international community on a coordinated Global Health Security Agenda (GHSA). Unfortunately, most of CDC's global health security activities have been supported by one-time supplemental funding that expires in 2019, not by annual appropriations. As these funds expire at the end of this fiscal year—jeopardizing the agency's efforts to develop new tools, train epidemiologists, buy equipment, upgrade labs, and stockpile drugs—GHTC urges the Subcommittee to continue to support an increase to annual appropriations for the Division of Global Health Protection (DGHP) within the Center for Global Health to ensure these activities continue. We also urge increased funding for the National Center for Emerging and Zoonotic Infectious Diseases (NCEZID), which complements DGHP's efforts globally with domestic preparedness efforts to ensure Americans are protected at home and abroad. We urge the Senate to match the increased support for these critical activities included in the House fiscal year 2020 LHHS bill: at a minimum, funding of $513.62 million for CGH and $644.62 million for NCEZID.

BARDA.—BARDA plays an unmatched role in global health R&D by providing an integrated, systematic approach to the development and purchase of critical medical technologies for public health emergencies. By leveraging unique contracting authorities and targeted incentive mechanisms, BARDA partners with diverse stakeholders from industry, academia, and nonprofits to bridge the "valley of death" between basic research and advanced-stage product development for medical countermeasures—an area where more traditional U.S. Government research enterprises do not operate.

With these unique assets, BARDA has played a vital role in the development of urgently needed countermeasures for emerging infectious diseases (EIDs) like Ebola and Zika, developing at least three Ebola vaccine candidates, at least six diagnostics for Zika, and at least five Zika vaccine candidates in under 2 years. To date, BARDA's work in advancing tools to protect against the threat of EIDs has largely been funded through emergency funding. To ensure the continuation of this critical work and forward-looking investments, GHTC supports the creation of a separate line item dedicated funding for EIDs within BARDA.

Innovation as a smart economic choice: In addition to bringing lifesaving tools to those who need them most, investment in global health R&D is also a smart economic investment in the United States. $0.89 cents of every U.S. dollar invested in global health R&D goes directly to U.S.-based researchers. U.S. Government investment in global health R&D between 2007 and 2015 generated an estimated 200,000 new jobs and $33 billion in economic growth. Furthermore, investments in global health R&D today can help achieve significant cost-savings in the future. New therapies to treat drug-resistant TB, for example, have the potential to reduce the price of TB treatment by 90 percent and cut health system costs significantly.

Now more than ever, Congress must make smart budget decisions. Global health research that improves the lives of people around the world—while at the same time supporting U.S. interests, creating jobs, and spurring economic growth at home—is a win-win. On behalf of the members of the GHTC, I would like to extend my gratitude to the Subcommittee 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 HEAD START

Dear Chairman Blunt, Ranking Member Murray, and Members of the Subcommittee, on behalf of the Head Start community, thank you for the opportunity to submit written testimony regarding funding for Head Start and Early Head Start (collectively referred to as "Head Start") in fiscal year 2020. For more than 50 years, Head Start has provided early learning opportunities for our country's most vulnerable children and comprehensive supports to families that address long-term economic stability and better health prospects, ultimately mitigating the devastating impacts that poverty can have on the future success of young children. As a community, we are grateful for the Subcommittee's tradition of strong bipartisan support for Head Start and its leadership on issues related to children and families. This Subcommittee has been a tremendous advocate for Head Start, Early Head Start, and other programs that give struggling young families and single parents sustained, unmatched support, providing the chance for children, like my grandchildren, not just to succeed in school but to thrive in life. To build on these critical successes, the National Head Start Association (NHSA) recommends $11,113,095,000 in Head Start funding for fiscal year 2020.

At a time when the challenges our country faces are quickly evolving, Head Start's mission to provide opportunities to our Nation's most vulnerable children and families has remained steadfast. This has been increasingly evident, especially as we grapple with the challenges created by rising rates of substance use disorders in particular communities across the country. For many families, like mine, at the heart of the response to this crisis is Head Start, which has been empowered by its unique relationships and its community-based approach to addressing the current epidemic.

I have been involved in Head Start since 2014 and have since become a Parent Ambassador and a Policy Council Chairperson for Head Start. I currently serve on the Ohio Head Start Association's board as a Region V Parent Representative and am a Parent Peer Supporter for Summit County, Ohio. In addition, I am a Parent Representative and Vice President for the Family and Children First Council of Summit County, Ohio. However, all of these roles come second to my role as a stay-at-home grandmother of two energetic, beautiful children: Dominic (age 6) and Kennedy (age 5).

Life has a way of surprising us when we least expect it. Six years ago, my husband and I were empty nesters and working full-time so that in our 50s and beyond we could relax and enjoy the simplicities of retired life. Then, when we were in the process of planning our dream vacation to Ireland, Scotland, and England, our lives were changed forever.

Both Dominic and Kennedy were born drug dependent and spent six weeks in the Newborn Intensive Care Unit at Akron Children's Hospital. While they suffered through withdrawals, their parents were nowhere to be found. It became my husband's and my job to feed and comfort both babies while they were shaking and crying, suffering from neonatal abstinence syndrome (NAS). While we were aware of the situation, we kept hoping that the children's births would trigger better behavior from their parents. Unfortunately, drug addiction is a force more powerful than many of us can imagine.

The first few years of their lives were full of traumatic experiences that still affect them today. Sadly, the first year of Dominic's life was spent day and night in a dark room, in a crib with little or no physical contact of any kind. He has extreme learning disabilities, sensory processing disorder, moderate autism, and most recently a diagnosis of attention-deficit/hyperactivity disorder (ADHD). He did not speak until he was 3 years old and many other milestones, like crawling and walking, were also extremely delayed. Both Dominic and Kennedy were physically abused by their father, as well as physically and emotionally neglected by their mother, resulting in a number of behavioral issues. In 2016, after years of back and forth with the children's parents, my husband and I were given permanent custody of both children.

My husband and I had no idea where to turn for help. That's when a local nonprofit recommended Head Start, and our lives began to change drastically. With the love and support from Head Start staff, both children who had been so isolated that they had no idea how to interact with other children, now play freely with other kids, know their alphabet, can count to fifty, and speak in full sentences. None of this would have been possible without the support of the Head Start staff who were able to give Dominic and Kennedy the specialized attention they needed to overcome the numerous challenges they faced.

Unfortunately, stories like mine are all too common. While Head Start continues to be at the forefront of supporting children and families impacted by addiction, additional funding is needed to ensure that children and families have access to the kind of assistance that Head Start provided to our family.

In addition to a cost-of-living adjustment (COLA) of $191,000,000, the fiscal year 2020 recommendation for Head Start calls for a $900,000,000 increase in Quality Improvement Funds (QIF). QIFs are designed to meet existing needs by providing programs with the flexibility to address specific, dire local priorities, all with a goal of improving program performance.

$155,000,000 of these funds would be dedicated to meeting a number of local needs, including providing more classroom time to better support working families, staff training, facility improvements, and strengthening transportation safety. The remaining $745,000,000 of the QIF request is intended for trauma-informed practices, giving Head Start programs the ability to meet the increase in existing challenges stemming from childhood trauma. This would include funding for additional staff training, so that teachers—like Ms. Dancy who taught my grandchildren—have the tools and knowledge they need to support all children. Further, it would fund increased mental health consultations and provide for additional staffing for preschool classrooms.

As the primary caregiver of two children with high needs, it is abundantly clear that these funds are essential for Head Start programs to provide the level of care that Dominic and Kennedy were fortunate enough to receive. As their primary caretaker, I saw the difference that Head Start made in my grandchildren's lives, and I can only hope that every child in need is afforded the same opportunity for a happy and healthy life.

I am forever thankful for Head Start's impact on Dominic and Kennedy. Frankly, I am not sure where they would be, intellectually or emotionally, without the dedication of Head Start teachers and staff. When we joined Head Start, we became part of a family. Despite my grandchildren now being in kindergarten, their Head Start teachers still call periodically to check on them. It is due to their excellent teaching ability and caring love and support that our grandchildren received a "Head Start" in life and are still thriving because of it.

No child asks to be put in a situation like what Dominic and Kennedy went through. Every day my heart breaks because their parents are missing so many new and special moments, like a first haircut, first day of school, or my favorite: a goodnight kiss and hug and my granddaughter saying, "I'll see you in the morning for coffee, Grandma." We love them more than life itself and will continue to do everything in our power to give them the best childhood and life we can provide. And, it's because of the Head Start program and the staff's genuine care for the children they serve that I am able to share our journey and help other families who may benefit from Head Start.

Head Start is not simply a preschool program, but a stable, caring environment where you can truly become part of a family. Today, I ask the Subcommittee to increase funding to this remarkable program because there are so many children out there that deserve the same chance that our grandchildren have received. Thank you very much for your time and consideration.

[This statement was submitting by Andrea Fleming, Head Start Grandparent Representative.]

PREPARED STATEMENT OF THE HEALTH PROFESSIONS AND NURSING EDUCATION COALITION

The Health Professions and Nursing Education Coalition (HPNEC) is an alliance of nearly 70 national organizations representing schools, students, health professionals, and communities dedicated to ensuring that the healthcare workforce is trained to meet the needs of our diverse population. Together, the members of HPNEC advocate for adequate and continued support for the health professions and nursing workforce development programs authorized under Titles VII and VIII of the Public Health Service Act and administered by the Health Resources and Services Administration (HRSA). For fiscal year 2020, HPNEC encourages the subcommittee to adopt at least $690 million for current HRSA Titles VII and VIII programs.

HRSA's Title VII health professions and Title VIII nursing workforce development programs are structured to allow grantees to test educational innovations, respond to changing delivery systems and models of care, and address timely health threats in their communities. Titles VII and VIII programs emphasize interprofessional education and training, by bringing together knowledge and skills across disciplines to provide effective, efficient and coordinated care. Through scholarships, loan repayment programs, grants and contracts to academic institutions, students and nonprofit organizations, HRSA's workforce development programs fill the gaps in the supply of health professionals not met by traditional market forces.

Our Nation is becoming increasingly diverse and faces a rapidly growing and aging population. Now more than ever support is needed for Title VII and Title VIII programs that improve the supply, distribution, and diversity of the workforce—to ensure health professionals are prepared to address the healthcare challenges of today and the future.

Primary Care Workforce.—The Primary Care Medicine Programs expand the primary care workforce, including general pediatrics, general internal medicine, family medicine, and physician assistants through the following programs: Primary Care Training and Enhancement (PCTE); academic units for PCTE; PCTE: Training Primary Care Champions; and Primary Care Medicine and Dentistry Career Development. The Primary Care programs are also intended to encourage health professionals to work in underserved areas. In fiscal year 2016, 49 percent of PCTE program completers were underrepresented minorities and/or from disadvantaged backgrounds.

The Primary Care Dentistry program invests in expanding programs in dental primary care for pediatric, public health, and general dentistry. The Pre- and Postdoctoral Training, Residency Training, Faculty Development, and Faculty Loan Repayment programs encourage integrating dentistry into primary care.

Diversity Pipeline Programs.—HRSA Titles VII and VIII programs play an important role in improving the diversity of the healthcare workforce and connecting students to healthcareers by supporting recruitment, education, training, and mentorship opportunities.

HRSA's diversity training programs support aspiring health professions students throughout the educational pipeline, helping to ensure a culturally competent healthcare workforce, including. Diversity programs include the Health Careers Opportunity Program (HCOP), Centers of Excellence (COE), Faculty Loan Repayment, Nursing Workforce Diversity, and Scholarships for Disadvantaged Students (SDS). Studies have demonstrated the effectiveness of such pipeline programs in strengthening students' academic records, improving test scores, and helping minority and disadvantaged students pursue careers in the health professions. Title VII diversity pipeline programs reached thousands of students in the 2016–2017 academic year, with SDS graduating 2,811 students and COE reaching more than 6,800 health professionals; 55 percent of which were located in medically underserved communities.

Title VIII's Nursing Workforce Diversity Program is intended to increase nursing education opportunities for individuals from disadvantaged backgrounds, including racial and ethnic minorities who are underrepresented among registered nurses. The program supports disadvantaged students through stipends and scholarships, and a variety of pre-entry and advanced education preparation. In academic year 2016–2017, the program trained 4,416 students, 100 percent of whom were either underrepresented minorities and/or from disadvantaged backgrounds.

Interdisciplinary, Community Health Linkages—Support for community-based training of health professionals in rural and urban underserved areas is funded through Title VII. By assessing the needs of the communities they serve, these programs are well positioned to fill gaps in the workforce and increase access to care for all populations. The programs emphasize interprofessional education and training, bringing together knowledge and skills across disciplines to provide effective, efficient, and coordinated care.

Programs such as Teaching Health Center Development; Graduate Psychology Education; Opioid Workforce Enhancement Program; Mental and Behavioral Health Education and Training; Behavioral Health Workforce Education and Training (BHWET); and Allied Health Training work directly with members of local communities to help meet their immediate health needs.

The community-based training programs 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. Area Health Education Centers (AHEC), which support workforce development and training for medical and public health professionals in rural areas, provided continuing education to 214,789 practicing health professionals across the country.

Public Health Workforce Development programs support education and training in public health and preventive medicine through different initiatives, including the only funding for physicians to work in State and local departments of health. In academic year 2016–2017, Public Health Workforce grantees delivered unique continuing education courses to 226,635 practicing professionals in the workforce.

Workforce Information and Analysis.—The Workforce Information and Analysis program supports the compilation and analysis of data on the Nation's health workforce, including longitudinal evaluation of the Title VII and Title VIII programs through the National Center for Health Workforce Analysis and the Regional Centers for Health Workforce Analysis.

Geriatrics Workforce Development.—Title VII Geriatric Workforce programs integrate geriatrics and primary care to provide coordinated and comprehensive care for older adults. The geriatrics programs provide training across the provider continuum (students, faculty, providers, direct service workers, patients, families, and lay and family caregivers), focusing on interprofessional and team-based care and on academic community partnerships to address gaps in healthcare for older adults. To advance the training of the current workforce, the Geriatrics Workforce Enhancement Program (GWEP) provided 1,578 unique continuing education courses, including 467 on Alzheimer's disease and related dementia, to 173,078 faculty. In academic year 2016–2017 alone, Title VII's GWEP trained 30,082 students and fellows in geriatric-specific degree programs, field placements, and fellowships.

Nursing Workforce Development.—Title VIII nursing workforce development programs provide Federal support to address all aspects of nursing workforce demands, including education, practice, recruitment, and retention, with a focus on rural and medically underserved communities. These programs include Advanced Nursing Education; Nursing Workforce Diversity; Nurse Education, Practice, Quality, and Retention; NURSE Corps; and Nurse Faculty Loan Program. In the 2016–2017 academic year, the Title VIII Advanced Education Nursing Traineeship and Title VIII Nurse Anesthetist Traineeship programs supported more than 4,595 nursing and nurse anesthesia students, all of whom received clinical training in primary care in medically underserved communities and/or rural settings.

HPNEC is grateful for the House of Representatives providing $680 million for Title VII and Title VIII programs, and an additional $55 million for the new Loan Repayment Program for Substance Use Disorder Treatment Work, the Mental and substance Use Disorder Workforce Training Demonstration, and Nurse Practitioner Optional Fellowship Program. These programs are essential to ensuring we have a trained health workforce to treat patients who are affected by substance use disorder. While we support the inclusion of these programs into Titles VII and VIII, it is imperative that they are an expansion of Titles VII and VIII and are not funded at the expense of current programs.

While HPNEC's members acknowledge the increasing demands and fiscal challenges facing appropriators, funding for HRSA's workforce development programs is critical in creating a culturally competent health workforce that meets the needs of all Americans. Therefore, HPNEC encourages the subcommittee to adopt at least a

$690 million for HRSA's current Title VII and VIII programs—and separate funding for any new programs—to continue the Nation's investment in our health workforce.

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 $2.5 million from its current $13.5 million to $16 million in funding for fiscal year 2020.

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.

HKNCs business imperative as the national special institution working with individuals who are Deaf-Blind is to ensure that each person has access to quality services and supports to achieve their goal to lead an independent and self-sufficient life.

The Helen Keller National Center (HKNC) is "On-the-Move" with a greatly strengthened national infrastructure of services for deaf-blind youths and adults. With recent additional Federal support in fiscal year 2018 and fiscal year 2019, the Center has made tangible progress implementing expanded field services. Newly deployed Deaf-Blind Specialists, a replicated Deaf-Blind Community Services Program in California and State interagency groups, are bringing much needed change and positive growth to services nationwide addressing unmet training needs of deaf-blind individuals. These advances are due to the "boots on the ground" resources HKNC has been able to deploy in communities throughout the country and with the strengthened partnerships, it has established among State and local service providers. Currently 48 inter-agency groups have been formed with the defined goal of supporting individuals who are deaf-blind to pursue and achieve successful employment and maximized independence through building and/or strengthening services and supports available at the State and local level. In addition, HKNC's National Community of Practice (NCOP) has 63 agency members working together to achieve collaborative learning and improvements in the quality of services for and among individuals who are deaf-blind. Last year in fiscal year 2018 HKNC provided resources and training to over 1100 professionals nationwide.

The Center's expertise derives from more than a half century of experience and the need to serve the estimated 2.4 million Americans who are deaf-blind. However, without the continued efforts of HKNC to build a sustainable national infrastructure, services will remain uneven and limited in scope. Expertise among vocational rehabilitation providers will continue to be inconsistent and in danger of not being maintained at the highest quality standard. The members of the deaf-blind community continually face barriers to independence and successful competitive employment because of the lack of services and qualified personnel. At this juncture additional Federal funding is critically needed to stay the course and to ensure that each person who is deaf-blind has the opportunity to live, work, and thrive in their community of choice.

A $2.5 million increase in funding for HKNC is needed to maximize current efforts and continue to address the growing unmet needs of the deaf-blind community across America. The funding will be channeled towards four priorities two of which are already in progress:

1. Continue field expansion through deployment of five additional deaf-blind specialists (20 in total). Deaf-Blind specialists report directly to the HKNC Regional Representative and are charged with providing employment and inde-

pendent living services in the designated State home communities to those who are deaf-blind. In addition, deaf-blind specialists provide follow up services to individuals who have completed training at HKNC who upon returning home are ready to work and enjoy a full community life.

2. Replication of the HKNC Community Services Program (CSP) in two additional States (4 in total) to expand local resources and offer direct services to deaf-blind persons and their families. Employment Services including job placement, Independent Living Services, Orientation & Mobility, and Casework services will be provided by two multi-disciplinary teams in two additional State locations. Current CSPs are located in downstate N.Y. and Los Angeles/San Diego, California.
3. The establishment of a the HKNC Training, Innovation & Research Center (TRIC), a State-of-the art adaptive technology training center for deaf-blind individuals, the professionals who work with them, and manufacturers of technology products and IT personnel. Not only will this center prepare deaf-blind individuals with technical literacy compatible with workforce competencies it will train adaptive technology trainers and offer feedback and review to the universal design and accessibility of products for deaf-blind users to manufacturers of technology.
4. The implementation of a Support Service Provider (SSP) program for participants at HKNC's comprehensive vocational rehabilitation program in Sands Point N.Y. and for those on its staff who are deaf-blind, to ensure accessibility and full inclusion in their living and working environment. An SSP provides visual and auditory environmental information to HKNC's deaf-blind staff for the accessibility necessary to carry out job responsibilities such as observing and coaching staff, observing lessons, gaining awareness of person present in a setting and any non-verbal information, visual or auditory that is contextual and supports the deaf-blind person's understanding and engagement. By developing a model SSP program for deaf-blind participants in the HKNC comprehensive vocational rehabilitation program including its own deaf-blind employees, the center will be able to offer staff an accessible work environment and maintain highest standards as a national model employer for individuals who are deaf-blind. In addition, HKNC will develop and disseminate best practices to other State and local programs

By investing in these priority areas, U.S. Senate will be advancing HKNC's ability to deliver its service model nationwide, to meet the employment and independent living needs of individuals who are deaf-blind. Creating opportunities for individuals to learn skills and have access to advanced technology as well as providing effective support services allows each person to engage fully in their living and working environments, achieve success, and enjoy a greatly enhanced quality of life.

With increased funding to $16 million 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 and its national partners are working collaboratively. The result is a national impact resulting in systematic change and capacity building across the country.

HKNC deeply appreciates the shared commitment by U.S. Senate to create a national sustainable infrastructure of services to deaf-blind citizens. We have momentum, ability and vision. We are make progress towards fidelity, sustainability and replication. The last requirement of funding for this next phase will make a highly significant impact and ensure that all Americans who are deaf-blind have an equal opportunity to live self-actualized lives as fully contributing, and included citizens.

[This statement was submitted by Susan Ruzenski, Executive Director, Helen Keller National Center.]

PREPARED STATEMENT OF THE HIGHER LEARNING ADVOCATES

Higher Learning Advocates (HLA) would like to thank the 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 2020 funding. Higher Learning Advocates (HLA) is a non-profit advocacy organization working to shift Federal policy from higher education to higher learning—education and training beyond high school that leads to a degree, credential, or employment. With more students participating in higher education than ever before, we strive to strengthen the connection between Federal policy and the needs of today's students, employers, and communities. We advocate for Federal policies and programs that create transparent pathways to success, incentivize innovation, protect students and taxpayers, and improve outcomes.

HLA urges the subcommittee to make significant investments in key higher education and child care programs as part of the fiscal year 2020 appropriations process. These investments are critical if we are to advance policies to reflect the needs of today's students and encourage a system of higher learning that is affordable and responds to the current needs. Specifically, HLA is requesting $7.7 billion for the Child Care and Development Block Grant (CCDBG), $150 million for the Child Care Access Means Parents in Schools (CCAMPIS) program, and $10 million for the Open Textbooks Pilot Program. In addition, we strongly urge the Subcommittee to support and improve the Pell Grant program, leaving the current Pell Grant surplus untouched so it is available to fund future Pell needs and not used as a piggy bank for other funding priorities.

Before we focus on these individual programs, we need to highlight the importance of raising the non-defense discretionary (NDD) funding limits for fiscal year 2020 and fiscal year 2021. As you know, NDD funding would be cut by $55 billion compared to fiscal year 2019 spending levels under the Budget Control Act. Even with the U.S. House of Representatives establishing the overall spending level for the full House appropriations committee and House subcommittee allocations, an eventual agreement by the House, Senate, and Administration to increase statutory NDD spending limits for fiscal year 2020 is still necessary to avoid these cuts. Absent a bipartisan agreement to increase the non-defense discretionary spending caps, investments in education and other related critical priorities would suffer. We hope an eventual bipartisan agreement to raise these spending limits is possible in the near future to allow Congress to make the important investments we highlight, and others, possible.

The needs of today's students are changing. Recent data by the Institute for Women and Policy Research show that almost a quarter of college students are parents themselves. Access to high-quality, affordable, and accessible child care can be a critical element to ensuring that a student is able to attend and complete higher education.

Our organization requests increasing funding for the Child Care and Development Block Grant (CCDBG) to support all parents—including student parents—to $7.7 billion. CCDBG is a Federal program that provides State grants to help low-income student parents afford the cost of child care services, so they can work, train for work, or attend school. This is the same level that would be appropriated under the House Committee—passed LHHS bill. Low-income parents, including student parents, greatly benefit from CCDBG funding, which provides them with low-cost and easy-to-access child care. Unfortunately, a large share of eligible children from low-income families do not receive child care assistance, and the number of children served by CCDBG continues to decline. This funding boost is crucial to respond to these realities.

We also request increased funding for the Child Care Access Means Parents in Schools (CCAMPIS) program to $150 million—the amount needed to provide child care support to approximately 2 percent of Pell-eligible student parents of children ages 0–5. The CCAMPIS program provides vital support for the participation and success of low-income parents in postsecondary education through the provision of campus—based child care, which is widely recognized as one of the most important supports for parenting college students. In 2001, funding for CCAMPIS peaked at $25 million but declined significantly in 2003 to $16 million, where it remained relatively stable until fiscal year 2017. In fiscal year 2018, CCAMPIS funding was increased to $50 million. CCAMPIS funding must continue to increase to best serve today's student parents.

Additionally, we urge you to maintain the initial Federal investment for the Open Textbooks Pilot program at $10 million in fiscal year 2020 appropriations to help institutions develop and utilize open educational resources. The cost of traditional textbooks is a burden for today's students—at community colleges, textbook costs can account for up to 80 percent of the cost of attendance. The prices of textbooks have increased by 88 percent between 2006 and 2016, and students typically spend $1,240–$1,440 on books and supplies per year. About 48 percent of Pell Grant recipients and 52 percent of underrepresented minorities said that open educational resources (OER) significantly impact their ability to afford college. Federal investment in the Open Textbooks Pilot program will afford students better access to educational materials needed to succeed in postsecondary education.

Finally, we urge that as you consider funding for the Pell Grant program, you focus on supporting and improving the program; take action to continue inflation indexing to avoid further erosion of the Pell Grant's purchasing power; and look for ways to increase the maximum award to benefit today's students. Additionally, we urge that any portion of the current Pell Grant surplus is not rescinded or redirected toward any other priorities. Recent proposals have utilized portions of the surplus to pay for other priorities, rather than keeping these funds within the Pell Grant program to pay for the eventual rise in program costs that the Congressional Budget Office and others predict for the program. Cutting the surplus will only hurt the long-term viability of the Pell Grant program, jeopardizing the critical role that Pell plays in financing the cost of a college education for low-income students. Rather than looking to the Pell Grant program to reduce the Nation's deficit or pay for new projects, Congress should instead ensure that this critical feature of the program is retained so that there is not a funding crisis or reduction in future years.

Thank you for the opportunity to submit testimony in support of CCAMPIS, CCDBG, the Open Textbooks Pilot, and the Pell Grant. Congress must continue to invest in these programs in order to ensure today's students, including student parents and individuals from underserved populations, are able to access and complete postsecondary education.

We appreciate your consideration of this request and are happy to follow up on any questions you may have.

PREPARED STATEMENT OF THE HIV MEDICINE ASSOCIATION

The HIV Medicine Association (HIVMA) of the Infectious Diseases Society of America (IDSA) represents nearly 6,000 physicians, scientists and other healthcare professionals on the frontlines of the HIV epidemic. Our members provide medical care and treatment to people living with HIV in the U.S. and globally, lead HIV prevention programs and conduct research that has led to the development of effective HIV prevention and treatment options. For the fiscal year 2020 appropriations process, we urge you to increase funding for the Ryan White HIV/AIDS Program at the Health Resources and Services Administration (HRSA); increase funding for the Centers for Disease Control and Prevention's (CDC) HIV, hepatitis and STD prevention programs; increase investments in HIV research supported by the National Institutes of Health (NIH); appropriate new funding to support the "Ending the HIV Epidemic" Initiative; and heighten our response to the opioid epidemic including the infectious diseases consequences associated with it and addressing workforce shortages by funding the SUPPORT Act's Loan Repayment for Substance Use Treatment Disorder Treatment Workforce Program at least at $25 million as authorized. Though we face continued challenges in HIV prevention and care, we are in strong support of the administration's recognition that we have the tools to end the epidemic. Adequate funding increases for relevant Federal agencies are needed now more than ever to achieve these goals.

Our investments in evidence-based public health approaches to HIV prevention, treatment, care, and research over the last 35 years have produced groundbreaking scientific discovery, saved millions of lives, and offset tremendous costs to the healthcare system by preventing new infections. We know that early diagnosis and access to HIV treatment allows persons with HIV to live healthy and productive lives, is cost-effective, and directly benefits public health by stopping new HIV transmissions when people living with HIV maintain viral suppression. Despite our progress, in recent years, new HIV diagnoses.have plateaued rather than declined. Just over half of people living with HIV in the U.S. are benefiting from treatment,[1] and disparities among vulnerable populations have widen. The funding requests in our testimony largely reflect the consensus of the Federal AIDS Policy Partnership, a coalition of HIV organizations from across the country.

Health Resources and Services Administration—HIV/AIDS Bureau:

To continue providing comprehensive, life-saving treatment and care for over 550,000 people living with HIV, and to begin bringing many more people into care through the Ending the HIV Epidemic Initiative, we request a $215.8 million increase over fiscal year 2019 levels for the Ryan White HIV/AIDS Program for a total of $2.535 billion. At this critical time of launching the "Ending the HIV Epidemic" in the U.S. initiative, bolstering the Ryan White Program with new funding is necessary to build workforce capacity and expand access to quality, expert care for people diagnosed with HIV.

In particular, HIVMA urges an allocation of $225.1 million, or a $24 million increase over current funding, for Ryan White Part C programs. Part C-funded HIV

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[1] Centers for Disease Control and Prevention. HIV Continuum of Care, U.S., 2014, Overall and by Age, Race/Ethnicity, Transmission Route and Sex. https://www.cdc.gov/nchhstp/newsroom/2017/HIV-Continuum-of-Care.html.

medical clinics are struggling to meet the demand of increasing patient caseloads. The team-based and patient-centered Ryan White care model has been highly successful at improving clinical outcomes for a population with complex healthcare needs. Persons with HIV who receive Ryan White services are more likely to be prescribed HIV treatment and to be virally suppressed. Between 2010 and 2017, the viral suppression rate for all Ryan White clients increased from 70 percent to 86 percent.[2] We also know that the annual healthcare costs for persons who are diagnosed late and/or do not have reliable access to care and treatment are nearly 2.5 times greater than that of healthier persons with HIV.[3] Increased Ryan White Part C funding also is urgently needed to meet the increasing demand for substance use disorder and mental health treatment at Ryan White clinics.

We also recommend funding the administration's request of $70 million in new funding for the "Ending the HIV Epidemic" initiative, which will bolster Ryan White services and providers in the 48 counties, Washington DC, San Juan, and seven rural States in preparation of bringing thousands of newly diagnosed people with HIV into quality care and with adequate support services.

Health Resources and Services Administration—Bureau of Primary Health Care:

We recommend appropriating $50 million in new funding for HRSA's Community Health Center program for the End the HIV Epidemic initiative. The administration's budget proposes repurposing $50 million existing dollars for community health centers in order to scale up pre-exposure prophylaxis (PrEP) services for people at high risk of acquiring HIV, which is a critical intervention and is a focal point of the Ending the HIV Epidemic initiative. Community health centers, especially those already funded by the Ryan White Program, are critical entry points for people with limited resources or without other sources for care to get tested and initiate PrEP. CDC estimates only 10 percent of those who could benefit from PrEP have been prescribed PrEP, and those who need it most—Black and Latino gay and bisexual men at high risk—are prescribed it at a much lower rate.[4] Scaling it up in the targeted counties and States in the most affected populations is critical to ending the HIV epidemic. Without a vaccine on the horizon, PrEP for HIV is our most effective prevention tool.

Centers for Disease Control and Prevention—National Center for HIV/AIDS, Viral Hepatitis, Sexually Transmitted Diseases, and Tuberculosis Prevention:

In order to meaningfully address the HIV, viral hepatitis and STDs syndemics, as well as the co-occurring crisis of addiction and injection drug use associated with the opioid epidemic, we request a $496 million overall increase above fiscal year 2019 levels for a total of $1.628 billion.

For the Division of HIV/AIDS Prevention (DHAP), we request a total of $1.012 billion, which is an $224 million increase over fiscal year 2019 levels. DHAP conducts our national HIV surveillance and funds State and local health departments and communities to conduct evidence-based HIV prevention activities. New annual infections recently fell below 40,000 for the first time in decades, but since then our outcomes have stagnated.[5] CDC's high impact prevention strategies work, but with flat funding, we cannot reach more people at risk for HIV. We also recommend appropriating the $140 million requested by the administration for the "Ending the HIV Epidemic" initiative, which will allow CDC to jumpstart new efforts to scale up HIV testing, implement PrEP programs, and link people newly diagnosed with HIV immediately to HIV care.

Additionally, we urge the appropriation of the requested $58 million for the CDC to fund surveillance and programming to monitor and prevent opioid-related infectious diseases. The proportion of new HIV and infections due to injection-drug use has grown in recent years and new viral hepatitis infections have increased significantly.[6] Bacterial infections like endocarditis still have no national surveillance, but anecdotally our members report significant increases in these costly infections.

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[2] Health Resources and Services Administration. Ryan White HIV/AIDS Program Annual Client-Level Data Report 2016. https://hab.hrsa.gov/sites/default/files/hab/data/datareports/RWHAP-annual-client-level-data-report-2016.pdf.

[3] Gilman BH, Green, JC. Understanding the variation in costs among HIV primary care providers. AIDS Care, 2008:20;1050–6. doi: 10.1080/09540120701854626.

[4] CDC. HIV prevention pill not reaching most Americans who could benefit—especially people of color. https://www.cdc.gov/nchhstp/newsroom/2018/croi-2018-PrEP-press-release.html.

[5] CDC. HIV Incidence: Estimated Annual Infections in the U.S., 2010–2016. https://www.cdc.gov/nchhstp/newsroom/2019/HIV-incidence.html.

[6] CDC. Injection Drug Use and HIV Risk. https://www.cdc.gov/hiv/risk/idu.html.

Policy—Syringe Service Programs:

HIVMA applauds the subcommittee's work in advancing report language that allows for the use of Federal funding for syringe services programs as an important prevention and public health intervention. We support its continuation and expansion to include the purchase of syringes and other equipment.

For the Division of Viral Hepatitis (DVH), we request a total of $134.0 million, which is a $95 million increase over fiscal year 2019 levels. Last year, CDC announced that in 2016, there were over 41,000 new cases of hepatitis C, a 21 percent increase over 2015 and a 350 percent increase since 2010. New HCV and hepatitis B infections are being driven by injection drug use throughout the country, and especially in regions hardest hit by the opioid epidemic.[7] A significant increase in resources is needed so that CDC can adequately fund and support viral hepatitis education, prevention, testing, and surveillance activities. With existing resources, the United States is simply not equipped to monitor viral hepatitis cases and the impact of these infections, much less appropriately cure and sufficiently prevent new infections.

For the Division of STD Prevention (DSTDP), we request a total of $227.3 million, which is a $70 million increase over fiscal year 2019 levels. Last year, CDC again reported the greatest ever number of new STD cases, with over 1.7 million cases of chlamydia, 555,000 cases of gonorrhea, and over 30,000 cases of syphilis, including 918 cases of congenital syphilis (mother-to-child transmission). This is a national public health emergency, and should be declared as such. CDC and jurisdictional health departments need a significant investment of new resources to expand local public health capacity to conduct screening, linkage to treatment, and partner services.

National Institutes of Health—Office of AIDS Research:

In order to continue funding 21st century discoveries that will help us end the HIV epidemic, such as improved HIV prevention modalities and treatment options, we request an overall fiscal year 2020 budget level of at least $2.5 billion above fiscal year 2019 levels for the National Institutes of Health (NIH). Consistent with the most recent Trans-NIH HIV/AIDS Research Professional Judgment Budget for fiscal year 2020, we ask that at least $3.502 billion be allocated for HIV research in fiscal year 2020, an increase of $457 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 research since fiscal year 2015 threatens to slow progress toward a vaccine and a cure, erode our capacity to sustain our Nation's leadership in HIV research and innovation, and discourage the next generation of scientists from entering the field. We also ask that the subcommittee include the language present in the House Appropriations L–HHS subcommittee's report that "directs NIH to increase funding for HIV/AIDS research by at least the same percentage as the increase in NIH overall funding."

Indian Health Service—Eliminating HIV and Hepatitis C in Indian Country:

We support and urge the appropriation of the $25 million in new funding for IHS to establish a new HIV and hepatitis C elimination initiative as part of the Ending the HIV Epidemic initiative.

Conclusion:

We have the tools to end the HIV epidemic in the U.S. To accomplish this, we must substantially increase funding to support comprehensive prevention and care programs, grow a qualified workforce and create a healthcare system which routinely screens people for HIV and provides access to those living with HIV uninterrupted access to care and treatment. In addition, addressing co-occurring epidemics like viral hepatitis, STDs, and substance use is critical. We urge the sub-committee to invest in a robust public health system and biomedical research to make this a reality.

[This statement was submitted by W. David Hardy, MD, Chair, HIV Medicine Association.]

PREPARED STATEMENT OF THE HUMAN FACTORS AND ERGONOMICS SOCIETY

On behalf of the Human Factors and Ergonomics Society (HFES), we are pleased to provide this written testimony to the Senate Subcommittee on Labor, Health and

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[7] Centers for Disease Control and Prevention. Viral Hepatitis Surveillance Report 2016. https://www.cdc.gov/hepatitis/statistics/2016surveillance/pdfs/2016HepSurveillanceRpt.pdf.

Human Services, Education, and Related Agencies for the official record. HFES urges the Subcommittee to provide $460 million for the Agency for Healthcare Research and Quality (AHRQ) and $346.3 million for the National Institute for Occupational Safety and Health (NIOSH), including a $2 million increase over the fiscal year 2019 level for the Education and Research Centers (ERCs); the Agriculture, Forestry and Fishing (AFF) Program; and the Total Worker Health Program in fiscal year 2020.

AHRQ funds research to protect and promote patient safety and care, while identifying and evaluating efficiencies to save lives and reduce costs. HFES requests $460 million, which is consistent with the fiscal year 2010 level adjusted for inflation. This funding level will allow AHRQ to rebuild portfolios terminated after years of cuts and will help the agency avoid a funding cliff that will result in more than a 25 percent cut to its program level budget when the Patient-Centered Outcomes Research (PCOR) Trust Fund is at risk of expiring at the end of fiscal year 2019. HFES also urges the Subcommittee to continue to fund AHRQ as its own agency, rather than integrating it into the National Institutes of Health (NIH), as proposed in the President's fiscal year 2020 budget request.

Additionally, HFES requests $346.4 million for NIOSH, including a $2 million increase over the fiscal year 2019 level for the Education and Research Centers (ERCs); the Agriculture, Forestry and Fishing (AFF) Program; and the Total Worker Health Program. The fiscal year 2020 President's budget request proposes reducing the NIOSH budget and eliminating many NIOSH programs, which would limit the ability of workers to avoid exposures that can result in injury or illnesses, push back improved working conditions, eliminate occupational safety and health educational services to U.S. businesses, and ultimately raise healthcare costs.

HFES and its members recognize and appreciate the challenging fiscal environment in which we as a Nation currently find ourselves. However, we believe strongly that investment in scientific research serves as an important driver for innovation and the economy as well as for protecting and promoting the health, safety, and well-being of Americans. We thank the Subcommittee for its longtime recognition of the value of scientific and engineering research and its contribution to innovation and public health in the U.S.

THE VALUE OF HUMAN FACTORS AND ERGONOMICS SCIENCE

HFES is a multidisciplinary professional association with over 4,500 individual members worldwide, including psychologists and other scientists, engineers, and designers, all with a common interest in designing safe and effective systems and equipment that maximize and adapt to human capabilities.

For over 50 years, the U.S. Federal Government has funded scientists and engineers to explore and better understand the relationship between humans, technology, and the environment. Originally stemming from urgent needs to improve the performance of humans using complex systems such as aircraft during World War II, the field of human factors and ergonomics (HF/E) works to develop safe, effective, and practical human use of technology. HF/E does this by developing scientific approaches for understanding this complex interface, also known as "human-systems integration." Today, HF/E is applied to fields as diverse as transportation, architecture, environmental design, consumer products, electronics and computers, energy systems, medical devices, manufacturing, office automation, organizational design and management, aging, farming, health, sports and recreation, oil field operations, mining, forensics, and education.

With increasing reliance by Federal agencies and the private sector on technology-aided decisionmaking, HF/E is vital to effectively achieving our national objectives. While a large proportion of HF/E research exists at the intersection of science and practice—that is, HF/E is often viewed more at the "applied" end of the science continuum—the field also contributes to advancing "fundamental" scientific understanding of the interface between human decisionmaking, engineering, design, technology, and the world around us. The reach of HF/E is profound, touching nearly all aspects of human life from the healthcare sector, to the ways we travel, to the hand-held devices we use every day.

CONCLUSION

HFES urges the Subcommittee to provide $460 million for AHRQ and $346.3 million for NIOSH, including a $2 million increase for the Education and Research Centers (ERCs); the Agriculture, Forestry and Fishing (AFF) Program; and the Total Worker Health Program in fiscal year 2020. These investments fund important research studies, enabling an evidence base, methodology, and measurements for improving healthcare, safety, and public health for Americans.

On behalf of the HFES, we would like to thank you for the opportunity to provide this testimony. Please do not hesitate to contact us should you have any questions about HFES or HF/E research. HFES truly appreciates the Subcommittee's long history of support for scientific research and innovation.

[This statement was submitted by Kermit Davis, PhD, President, and Steven C. Kemp, CAE, Executive Director, Human Factors and Ergonomics Society.]

Prepared Statement of the Infectious Diseases Society of America

On behalf of the Infectious Diseases Society of America (IDSA), which represents more than 11,000 physicians, scientists, public health practitioners and other providers involved in infectious diseases prevention, care, research and education, I urge the Subcommittee to provide robust fiscal year 2020 funding for public health and biomedical research activities that save lives, contain healthcare costs and promote economic growth. IDSA asks the Subcommittee to provide at least $8.2 billion for the Centers for Disease Control and Prevention (CDC), at least $41.7 billion for the National Institutes of Health (NIH), and at least $750 million for the Biomedical Advanced Research and Development Authority (BARDA).

CENTERS FOR DISEASE CONTROL AND PREVENTION

Antibiotic Resistance Solutions Initiative

We urge at least $200 million in funding for the Initiative in fiscal year 2020. IDSA members see the impact daily that antimicrobial resistance (AMR) has on patients. Antimicrobial resistance is a public health crisis. In November 2018, a Journal of Infection Control and Hospital Epidemiology report found that as many as 162,044 people die in the U.S. each year as a result of antimicrobial resistance, making AMR the third leading cause of death in our country. To protect patients and save lives, the Federal response to AMR must be increased to prevent and detect multi-drug resistant infections. The requested funding would allow CDC to expand Healthcare-Associated Infections (HAI)/AMR prevention efforts in all 50 States, six large cities, and Puerto Rico. A deeper investment of $200 million will allow CDC to work with additional healthcare providers and facilities to implement effective antimicrobial stewardship programs to reduce inappropriate antibiotic use and prevent resistant infections. Increased funding is also needed to expand global surveillance and antibiotic stewardship activities. The CDC projects over the 5 years of the initiative, the most frequent resistant infections affecting our communities will be substantially reduced. Specifically, this funding will markedly limit infections due to healthcare-associated carbapenem-resistant Enterobacteriaceae (CRE) (est. 60 percent infection decline), Clostridium difficile and bloodstream methicillin-resistant Staphylococcus aureus (MRSA) (est. 50 percent decline in each) healthcare-associated multidrug-resistant Pseudomonas spp. (est. 35 percent decline), and multidrug-resistant Salmonella infections (est. 25 percent decline). These substantial payoffs mean a clear net positive for the Federal budget to recoup the direct costs of the program and a win for patients and their families.

Advanced Molecular Detection (AMD)

Funding of at least $32.5 million for the AMD program would allow CDC to determine the source of emerging diseases more rapidly, whether microbes are resistant to antibiotics, and how pathogens are moving through a population. AMD strengthens CDC epidemiologic and laboratory expertise to guide public health actions more effectively. Additional funding in fiscal year 2020 would help ensure State and local health departments have enhanced knowledge to harness DNA sequencing of pathogens facilitate early detection and response to surging disease outbreaks.

National Healthcare Safety Network

Fiscal year 2020 funding of at least $22.75 million for the National Healthcare Safety Network (NHSN) will enable CDC to expand tracking of healthcare-associated infections (HAIs), antibiotic use, and antibiotic resistance. The NHSN is the most widely used HAI tracking system in the country and provides facilities, States, regions, and the Nation with data needed to identify problem areas, by providing information on antibiotic use and resistance, measuring the progress of prevention efforts, and ultimately eliminating HAIs. As of April 1, 2018, 776 out of the over 5,500 U.S. hospitals have voluntarily reported antibiotic use data, and 317 hospitals have reported antibiotic resistance data to the CDC NHSN Antibiotic Use and Resistance (AUR) module. This represents only limited progress and falls strikingly short of the stated goal in the National Action Plan for Combating Antibiotic Resistant Bacteria for 95 percent of hospitals to report these data by 2020. Comprehensive data on antibiotic use and resistance are essential to inform, evaluate and enhance antibiotic stewardship activities and other efforts to address AMR.

Infectious Diseases and the Opioid Epidemic

The opioid epidemic is driving increasing rates of multiple infectious diseases including HIV, hepatitis B and C, and infections of the heart, skin and soft tissues, bones, and joints. IDSA is grateful to Congress and the Administration for enacting the SUPPORT Act, which expanded the Public Health Services Act to enhance the Federal response to infectious diseases commonly associated with injection drug use. Given the significant and growing burden of the opioid epidemic, IDSA strongly urges that Congress provide at least $58 million to address infectious diseases associated with the opioid epidemic. We also recommend report language to make clear that this funding should be used to support surveillance, prevention services, detection and linkages to care for the scope of viral, bacterial, and fungal infectious diseases associated with injection drug use.

National Center for HIV/AIDS, Viral Hepatitis, STD and TB Prevention

Rising cases of sexually transmitted diseases (STD) underscore the need for new resources for a robust public health response. Gonorrhea diagnoses increased by 67 percent from 2016 to 2017, the third consecutive year of increases. Growing antibiotic resistance has left only one highly effective antibiotic to treat gonorrhea in the U.S., and reports of gonorrhea infections in other countries that are resistant to all antibiotics are deeply concerning. Primary and secondary syphilis cases have increased by 76 percent from 2016 to 2017. The number of congenital syphilis cases is the highest it has been since 1997. New hepatitis C cases nearly tripled from 2010 to 2015, many due to injection drug use. CDC estimates that the actual number is much higher since hepatitis C has few early symptoms, and many newly infected individuals go undiagnosed. The tools necessary to end the hepatitis C epidemic exist, but resources are needed to expand surveillance and prevention efforts, identify individuals with hepatitis C, and link them to treatment. IDSA recommends at least $1.47 billion for this Center.

CDC Center for Global Health

IDSA urges the Subcommittee to provide at least $642 million in fiscal year 2020 funding to support programs at the CDC Center for Global Health that protect Americans by helping to stop health threats overseas before they reach American soil. The global health program is critical to ensure America's health security, including strengthening laboratory capacities, disease surveillance and field epidemiology activities in the developing world. As the ongoing Ebola outbreak in the Democratic Republic of Congo demonstrates, current investments in preparedness and response to outbreaks is essential. CDC is a key implementer of the Global Health Security Agenda that will expire in September 2019 if additional resources are not committed.

Epidemic Intelligence Service Loan Repayment

IDSA urges the Subcommittee to provide at least $5 million for the EIS program. The EIS is a two-year program within CDC's Division of Scientific Education and Professional Development in which health professionals learn epidemiology to respond to public health emergencies. EIS officers mobilized for the 2014–2015 Ebola response, as well as responses to Zika, the opioid epidemic, natural disasters and human-made biothreats such as anthrax. The 2018 EIS class includes only 62 officers (75–80 is optimal), setting the program back to the response capability of the 1980s. The Pandemic and All Hazards Preparedness and Advancing Innovation Act (PAHPAI) provides CDC authority to offer student loan repayment to EIS officers to strengthen their recruitment. New funding is needed to implement this authority.

Infectious Diseases Rapid Response Fund

The quick spread of emerging infectious diseases makes clear the need for the Rapid Response Fund. The Fund enables CDC and other Federal agencies to quickly address public health emergencies and infectious disease outbreaks at their source, and before they reach American shores, if possible. A deeper investment of at least $300 million is needed to ensure agencies, led by the CDC can move forward with brisk, well-organized initial response activities to contain the spread of infection; treat infected individuals and launch research for vaccines, diagnostics and therapeutics.

NATIONAL INSTITUTES OF HEALTH

National Institute of Allergy and Infectious Diseases (NIAID)

Within NIH, funding of at least $5.808 billion should be provided for NIAID. The NIAID plays a leading role in research for new rapid ID diagnostics, vaccines, and therapeutics. Given the threat to public health posed by growing antimicrobial resistance, a deeper investment in valuable research at NIAID through the Combating Antibiotic Resistant Bacteria Initiative will support relevant research into how to counter the ever-evolving threat posed by resistant microbes.

With increased funding in fiscal year 2020, NIAID would be able to establish a global network of emerging infectious diseases research centers with multidisciplinary teams to better understand emerging threats and how to stop them. The Institute would be able to fund an acute flaccid myelitis (AFM) natural history study. AFM is a severe weakness likely linked to viral infection, and it mostly impacts children. While the severe impacts of AFM have thus far struck a small number of patients, there is an opportunity for this virus to spread much more broadly. More research is needed to better understand the underlying viral causes to drive prevention and treatment. NIAID is also planning to expand efforts to support the next generation of researchers, but this will be challenging without additional resources. Support at the requested level would enable NIAID to increase funding and success rates for early and mid-career awards, and pilot a new innovator award to promote bold new ideas from early stage investigators. This kind of thinking is precisely what is needed to address growing ID threats.

Fogarty International Center

Congress should provide full funding of at least $84.9 million for the Center in fiscal year 2020. The Fogarty Center is instrumental to our Nation's global standing, global health security and our ability to detect and respond to pandemics. U.S. patients and researchers benefit from Fogarty funded breakthroughs on diseases including HIV, tuberculosis, malaria, cancer, diabetes, and heart disease. More than 80 percent of Fogarty's extramural grant budget goes to U.S. academic institutions and 100 percent of funding engages U.S scientists and researchers.

ASSISTANT SECRETARY FOR PREPAREDNESS AND RESPONSE

Biomedical Advanced Research and Development (R&D) Authority

BARDA is a critical initiator of public-private collaborations for antibiotic, diagnostic and vaccine R&D. IDSA recommends that the Subcommittee provide at least $750 million for BARDA in fiscal year 2020. Such funding is necessary to allow BARDA to pursue essential work on antibiotic development while maintaining its strong focus on medical countermeasures to address other biothreats. 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 on setting up a diverse portfolio with more than 20 high-quality antibacterial products.

CENTERS FOR MEDICARE AND MEDICAID SERVICES

Infectious diseases physicians underpin the ability of hospitals to provide complex medical care advances (e.g., transplant medicine, many surgical procedures) as well as enhancing the quality of care in hospitals. Further, in the community, for example, ID physicians serve to advance public health, foster appropriate use of antibiotics and continue the care of often highly complex patients after discharge from the hospital. Despite these crucial roles in broadly supporting medical care, ID physicians are undervalued. At a time when ID physicians are needed more than ever, there has been a 21.6 percent decline in the number of applicants to infectious disease fellowship training programs over a 5-year period ending in 2016.IDSA surveyed internal medicine residents in 2014 and found financial concerns were the chief barrier to pursuing ID. Further, the average salary of an ID physician (according to IDSA's 2017 compensation survey) is $100,000 less than the median salary of a specialty physician (according to the 2017 Medscape Physician Compensation Report). The chief driver of the compensation gap is the evaluation and management (E/M) codes, which cover more than 90 percent of ID physician services, which have not been updated in over a decade. IDSA was very grateful that the Subcommittee's report on the fiscal year 2017 LHHS bill included report language urging CMS to address this issue. Unfortunately, the 2019 Physician Fee Schedule Final Rule exacerbates the low value of E/M codes by maintaining level 5 E/M to account for the most complex patients and visits, but collapsing levels 2–4 E/M codes in 2021, which would result in reductions in payment for the Level 4 E/M. The final rule does not reflect Congress's urging to work with the medical community on a revised proposal and fiscal year 2017 report language urging CMS to address the undervaluation of E/M codes. IDSA urges the Subcommittee to encourage CMS to take time during the 2020 rule-making process to better understand how reimbursement for E/M services impacts the current ID workforce distribution and shortage. CMS must ensure that changes to the payment structure should not further exacerbate workforce shortages which may ultimately lead to not only significant patient access issues but increased morbidity and possibly mortality for vulnerable U.S. citizens afflicted with infectious diseases.

CONCLUSION

Thank you for the opportunity to submit this statement. The Nation's infectious diseases physicians and scientists rely on strong Federal partnerships to keep Americans healthy and urge you to support these efforts. Please forward any questions to Lisa Cox at lcox@idsociety.org.

[This statement was submitted by Cynthia Sears, MD, FIDSA, IDSA, Infectious Diseases Society of America.]

PREPARED STATEMENT OF THE INSTITUTE OF EDUCATION SCIENCE'S

We write today to express concern regarding the elimination of the Institute of Education Science's (IES) Researcher-Practitioner Partnerships in Education funding program. We believe that discontinuing this program will deny communities across the country the opportunity to generate valuable evidence that can be used to address local educational challenges. This decision appears to signal an IES unwillingness to fund research-practice partnerships as a strategy to provide education stakeholders the usable information they say they want and need.

In recent years more than 250 publicly or privately funded research-practice partnerships (RPPs) have operated at the local and State levels across the country. Among them are the 53 funded through the IES program that has been eliminated. Additionally, IES currently supports more than 80 partnerships through its operation of the Regional Educational Laboratory program.

RPPs are long-term collaborative partnerships between researchers in universities and research organizations and education stakeholders (educators, State and local education administrators, parents and community members, professional educator associations, government and business leaders, and others) to tackle important local challenges. RPPs are currently working on a variety of issues, such as strengthening the educator workforce, promoting college and career readiness and success, bolstering early childhood education, improving math and science instruction, and creating equitable learning environments.

These partnerships are built on the common-sense observation that education stakeholders are more likely to value and use research if they are involved in identifying which local educational challenges should be studied, playing a role in designing the research, and participating in communicating and engaging with education stakeholders in the use of the evidence produced. RPPs do more than produce research, they also facilitate the application of evidence in decisionmaking by creating engaging videos, webinars and activities that help evidence come to life.

Given their popularity, we were concerned to learn that the IES is abandoning support of RPPs by discontinuing funding of the Researcher-Practitioner Partnerships in Education program. This is despite the positive evidence contained in a 2017 IES-commissioned study that found the following benefits reported by participants of the first three funded cohorts of the program:

- Researchers and practitioners alike highly valued their participation in partnership work, with 100 percent of those surveyed either agreeing or strongly agreeing that they would participate in an RPP in the future.
- Practitioners named several benefits, including helping to shift organizational culture for research use and increasing access to resources and expertise aimed at understanding and addressing a specific problem of practice.
- Both researchers and practitioners also felt that the quality and applicability of research increased as a result of the partnership.

Beyond discontinuance of the funding program, over the past several months IES Director Schneider has criticized the RPP approach, raising questions regarding whether any future IES funds will be used to support research-practice partnerships. Such actions would fly in the face of common-sense, the enthusiasm demonstrated in many local communities for this approach, and the positive evidence generated by IES itself.

There is great potential negative impact of the elimination of funding for these promising RPP projects. For example past RPP grants allowed the University of Missouri, Columbia to partner with six school districts in Boone County; the University of Washington to partner with Seattle Public Schools and Spokane Public Schools through three separate grants; and Washington State University to partner with the Washington Education Service District 105. Future communities will be denied the opportunity to engage in similarly useful projects.

Based on these concerns, we urge you to include language in the appropriation report encouraging IES to "express support for research-practice partnerships (RPPs) and to reinstate the RPP program or some variation thereof that will advance the use of research in partnerships that include educators, policymakers, education research organizations, and others committed to applying evidence to improve education."

We appreciate your attention to this matter.

Sincerely.

[This statement was submitted by Steve Fleischman, Partner, Change Dynamics, LLC and Jim Kohlmoos, Principal, EDGE Partners, LLC.]

PREPARED STATEMENT OF THE INSTITUTE OF MUSEUM AND LIBRARY SERVICES

The Natural Science Collections Alliance appreciates the opportunity to provide testimony in support of fiscal year 2020 appropriations for the Institute of Museum and Library Services (IMLS). We encourage Congress to reject the President's request to eliminate the IMLS and to instead provide IMLS with at least $257 million in fiscal year 2020.

The Natural Science Collections Alliance is a non-profit association that supports natural science collections, their human resources, the institutions that house them, and their research activities for the benefit of science and society. Our membership consists of institutions that are part of an international network of museums, botanical gardens, herbaria, universities, and other institutions that contain natural science collections and use them in research, exhibitions, academic and informal science education, and outreach activities.

Museums strengthen our national economy. They provide core educational and outreach programs to engage the public and contribute more than $50 billion to the U.S. economy every year, support more than 726,000 American jobs, and generate $12 billion in tax revenue. It is of paramount importance to invest in museums given the enormous economic and educational contributions of these institutions.

IMLS provides funding that helps museums with public outreach programs and strengthens the capacity of museums to improve the well-being of their communities. Its Office of Museum Services awards grants to museums for preserving and digitizing collections, educational programming, professional development, and community outreach. In addition to providing grants, the agency conducts critical research, facilitates State and regional collaboration, and supports national initiatives that benefit museums. Implementing the President's request to eliminate IMLS is irresponsible and will lead to a loss of critical data, resources, and infrastructure the Nation requires to chronicle our shared experiences, advance research, and provide educational opportunities for people of all ages.

Investments in IMLS and its efforts to support scientific and educational advances in science collections, such as those that comprise natural history museums, are in the national interest. Scientific collections contribute to improved public well-being and national economic security. This important documentation of our Nation's heritage is irreplaceable; it cannot be reconstructed or reassembled at a later date. Specimens collected decades or centuries ago are increasingly used to develop and validate models that explain how species, including viruses, parasites, and pathogens have dispersed around the world, as well as how and when they might infect humans now and in the future.

The IMLS is the primary Federal agency that supports public education programs at museums and an important source of funding for preserving scientific collections. Investments in IMLS programs that support natural science collections research and education are essential if we are to maintain our global leadership in innovation.

Scientific collections enable us to tell the story of life on Earth. There are more than 1,600 biological collections in the United States, with a significant number of these constituting the research and education resources of our Nation's natural history museums. These resources are the result of more than 200 years of scientific investigation, discovery, and inventory of living and fossil species. Scientists have collected, studied, and curated more than one billion specimens within those collections. This work is on-going as new questions continue to be asked. The institutions that care for scientific collections are important research infrastructure for the United States that also provide students with hands-on training opportunities.

Natural science collections advance scientific research and education that informs actions to improve public health, agricultural productivity, natural resource management, biodiversity conservation, artistic and creative pursuits, and American economic innovation more generally. Current research involving natural science collections also contributes to the development of new cyberinfrastructure, data visualization tools, and improved data management practices. A few examples of how scientific collections have saved lives, enhanced food production, and advanced scientific discovery include:

—Scientists used museum specimens in U.S. collections to gather data on the distribution of the mosquito Culex quadrofaciatus, which is known to carry West Nile Virus and other pathogens. This allowed them to model the distribution of the mosquito under different climate scenarios to predict regions to which the species might spread. These models can assist public health officials working to prepare for disease outbreaks.

—Citrus bacterial canker disease wreaks havoc on fruit crops in Florida. Using plant specimens collected a century ago, scientists have analyzed the bacterium and traced its source. Knowledge of how the bacteria spreads allows scientists to develop effective control methods and to protect the U.S. citrus industry.

—In 2018, researchers from Boston University documented Tau proteins in the brains of fluid preserved museum specimens of Downy Woodpecker (Dryobates pubescens). These proteins are also found in humans with traumatic brain injuries. Because of the life history traits of woodpeckers, the researchers argue these birds may have evolved a level of resistance to traumatic head injuries that could offer insights for potential treatments of traumatic brain injury in humans.

Please support funding of at least $257 million for IMLS for fiscal year 2020.

Thank you for your thoughtful consideration of this request and for your prior support of the Institute of Museum and Library Services.

[This statement was submitted by John Bates, Ph.D., President, Natural Science Collections Alliance.]

PREPARED STATEMENT OF THE INTERNATIONAL FOUNDATION FOR GASTROINTESTINAL DISORDERS

FISCAL YEAR 2020 L-HHS APPROPRIATIONS RECOMMENDATIONS

—At least $41.6 billion in program level funding for the National Institutes of Health (NIH).

  —Proportional funding increase for the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK).

Chairman Blunt, Ranking Member Murray, and distinguished members of the Subcommittee, as you work with your colleagues to develop the fiscal year 2020 Labor-Health and Human Services (L–HHS) appropriations bill, please keep in mind the needs and concerns of the functional GI and motility disorders community. Nearly two decades ago, I was diagnosed with one of these diseases, irritable bowel syndrome (IBS). As a young adult, I underwent extensive testing and workups over many years in a difficult effort to discover what was causing my symptoms and how best to treat them. I often relied on self-treatment as best as I could, but this was not sustainable. Unfortunately, I am not alone in these experiences. As President of IFFGD, I have heard my story echoed back to me by thousands of others. Patients affected by these disorders often face similar delays in diagnosis, frequent misdiagnosis, and inappropriate treatments including unnecessary and costly surgery. These are common concerns for our community, and they underscore the need for increased research, improved provider education, and greater public awareness.

ABOUT THE FOUNDATION

The International Foundation for Gastrointestinal Disorders (IFFGD) is a registered nonprofit education and research organization dedicated to informing, assisting, and supporting people affected by gastrointestinal (GI) disorders. IFFGD works with patients, families, physicians, nurses, practitioners, investigators, regulators, employers, and others to broaden understanding about GI disorders, support and encourage research, and improve digestive health in adults and children.

ABOUT GASTROINTESTINAL (GI) AND MOTILITY DISORDERS

GI and motility disorders are the most common digestive disorders in the general population. These disorders are classified by symptoms related to any combination of the following: motility disturbance, visceral hypersensitivity, altered mucosal and immune function, altered gut microbiota, and altered central nervous system (CNS) processing. Some examples of functional GI disorders are: dyspepsia, gastroparesis, irritable bowel syndrome (IBS), gastroesophageal reflux disease (GERD), bowel incontinence, cyclic vomiting syndrome, abdominal phrenic dyssynergia (APD), and pelvic floor dysfunction. The costs associated with these diseases range from $25-$30 billion annually; economic costs are also reflected in work absenteeism and lost productivity.

NATIONAL INSTITUTES OF HEALTH

Strengthening the Nation's biomedical research enterprise through NIH fosters economic growth and sustains innovations that enhance the health and well-being of the American people. Functional GI disorders are prevalent in about 1 in 4 people in the U.S., accounting for 40 percent of GI problems seen by medical providers. NIDDK supports basic, clinical, and translational research on aspects of gut physiology regulating motility and supports clinical trials through the Motility and Functional GI Disorders Program.

Several of NIH's crosscutting initiatives are currently advancing science in meaningful ways for patients with gastrointestinal disorders. The Stimulating Peripheral Activity to Relieve Conditions (SPARC) Initiative supports research on the role that nerves play in regulating organ function. Methods and medical devices that modulate these nerve signals are a potentially powerful way to treat many chronic conditions, including gastrointestinal and inflammatory disorders. The Human Microbiome Project is also unlocking important discoveries that will help to inform and advance emerging treatment options for many in the community.

PATIENT PERSPECTIVE

I would like to share with you the patient perspective of one of our members, Brittany Aliano from New York. Brittany suffers from an unknown disorder of the GI-tract, and her experience exemplifies why the community drastically needs increased medical research, professional education, and public awareness.

"My primary diagnosis is Abdomino-Phrenic Dyssynergia (APD). When a normal person swallows, the diaphragm is supposed to relax (to accommodate the stomach filing with food) and the abdominals are supposed to contract (to keep all the abdominal contents inside the body). Unfortunately, in APD the opposite happens. So, when I eat, my diaphragm contracts and pushes all my organs out of my body. My abs also relax, resulting in a "pseudo-pregnancy." This happens every time I eat, so it is worse at the end of the day.

I have had to fight extremely hard to get medical care in the U.S., because most American doctors are not familiar enough with functional gastrointestinal disorders. In fact, I had to leave the country twice to get treatment! We need more awareness, research, and education in America surrounding these disorders.

No one should have to suffer like I have or go abroad to get care. We need more research and awareness stateside!"

Thank you for the opportunity to submit our community's perspective, as you consider appropriations priorities for fiscal year 2020. We look forward to continuing to work with you on these critical issues.

[This statement was submitted by Ceciel T. Rooker, President, International Foundation for Gastrointestinal Disorders.]

PREPARED STATEMENT OF THE INTERSTITIAL CYSTITIS ASSOCIATION

SUMMARY OF RECOMMENDATIONS FOR FISCAL YEAR 2020

—Provide $1.1 Million for the IC Education and Awareness Program and the IC Epidemiology Study at the Centers for Disease Control and Prevention (CDC)

—Provide $41.6 Billion for the National Institutes of Heatlh (NIH) and Proportional Increases Across All Institutes and Centers

—Support NIH Research on IC, including the Multidisciplinary Approach to the Study of Chronic Pelvic Pain (MAPP) Research Network and Chronic Pain

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Thank you for the opportunity to present the views of the Interstitial Cystitis Association (ICA) regarding interstitial cystitis (IC) public awareness and research. ICA was founded in 1984 and is the only nonprofit organization dedicated to improving the lives of those affected by IC. The Association provides an important avenue for advocacy, research, and education. Since its founding, ICA has acted as a voice for those living with IC, enabling support groups and empowering patients. ICA advocates for the expansion of the IC knowledge-base and the development of new treatments. ICA also works to educate patients, healthcare providers, and the public at large about IC.

IC is a condition that consists of recurring pelvic pain, pressure, or discomfort in the bladder and pelvic region. It is often associated with urinary frequency and urgency. This condition may also be referred to as painful bladder syndrome (PBS), bladder pain syndrome (BPS), and chronic pelvic pain (CPP). It is estimated that as many as 12 million Americans have IC symptoms. Approximately two-thirds of these patients are women, though this condition does severely impact the lives of as many as 4 million men. IC has been seen in children and many adults with IC report having experienced urinary problems during childhood. However, little is known about IC in children, and information on statistics, diagnostic tools and treatments specific to children with IC is limited.

The exact cause of IC is unknown and there are few treatment options available. There is no diagnostic test for IC and diagnosis is made only after excluding other urinary/bladder conditions. It is not uncommon for patients to experience one or more years delay between the onset of symptoms and a diagnosis of IC. This is exacerbated when healthcare providers are not properly educated about IC.

The effects of IC are pervasive and insidious, damaging work life, psychological well-being, personal relationships, and general health. The impact of IC on quality of life is equally as severe as rheumatoid arthritis and end-stage renal disease. Health-related quality of life in women with IC is worse than in women with endometriosis, vulvodynia, and overactive bladder. IC patients have significantly more sleep dysfunction, and higher rates of depression, anxiety, and sexual dysfunction.

Some studies suggest that certain conditions occur more commonly in people with IC than in the general population. These conditions include allergies, irritable bowel syndrome, endometriosis, vulvodynia, fibromyalgia, and migraine headaches. Chronic fatigue syndrome, pelvic floor dysfunction, and Sjogren's syndrome have also been reported.

IC PUBLIC AWARENESS AND EDUCATION THROUGH CDC

ICA recommends a specific appropriation of $1.1 million in fiscal year 2020 for the CDC IC Program. This will allow CDC to fund the Education and Awareness Program, per ongoing congressional intent, as well as the IC Epidemiology Study.

CDC shifted the focus of the IC program to an epidemiology study and away from education and awareness. The IC community is concerned that focusing solely on an epidemiology study instead of a renewed focus on education and awareness activities is detrimental to patients and their families. We have tried to speak with the CDC on collaborating along with the epidemiology study, however they would not meet with us. This is concerning because of the specific language that Congress has included for education and awareness activities through the program. We know that CDC has not received as generous increases as NIH over the past few fiscal years, but it is important the CDC supports both critical components of the IC Program. The CDC IC Education and Awareness Program is the only Federal program dedicated to improving public and provider awareness of this devastating disease, reducing the time to diagnosis for patients, and disseminating information on pain management and IC treatment options. ICA urges Congress to provide funding for IC education and awareness in fiscal year 2020.

The IC Education and Awareness program has utilized opportunities with charitable organizations to leverage funds and maximize public outreach. Such outreach includes public service announcements in major markets and the Internet, as well as a billboard campaign along major highways across the country. The IC program has also made information on IC available to patients and the public though videos, booklets, publications, presentations, educational kits, websites, self-management tools, webinars, blogs, and social media communities such as Facebook, YouTube, and Twitter. For healthcare providers, this program has included the development of a continuing medical education module, targeted mailings, and exhibits at national medical conferences.

The CDC IC Education and Awareness Program also provided patient support that empowers patients to self-advocate for their care. Many physicians are hesitant to treat IC patients because of the time it takes to treat the condition and the lack of answers available. Further, IC patients may try numerous potential therapies, including alternative and complementary medicine, before finding an approach that works for them. For this reason, it is especially critical for the IC program to provide patients with information about what they can do to manage this painful condition and lead a normal life.

IC RESEARCH THROUGH THE NATIONAL INSTITUTES OF HEALTH

ICA recommends a funding level of $41.6 billion for NIH in fiscal year 2020. ICA also recommends continued support for IC research including the MAPP Study administered by NIDDK.

The National Institutes of Health (NIH) maintains a robust research portfolio on IC with the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) serving as the primary Institute for IC research. Research currently underway holds great promise to improving our understanding of IC and developing better treatments and a cure. The NIDDK Multidisciplinary Approach to the Study of Chronic Pelvic Pain (MAPP) Research Network studies the underlying causes of chronic urological pain syndromes, including epidemiology. The MAPP Study has continued to include cross-cutting researchers who are currently identifying different phenotypes of the disease. Phenotype information will allow physicians to prescribe treatments with more specificity. Research on chronic pain that is significant to the community is also supported by the National Institute of Neurological Disorders and Stroke (NINDS) as well as the National Center for Complementary and Integrative Health (NCCIH). The vast majority of IC patients often suffer major and multiple quality of life issues due to this condition. Many IC patients are unable to work full time because pain affects their mobility, sleep, cognition, and mood. These are people that simply want to lead productive lives, and need pain medication to do so. Due to the fact that IC is categorized as a non-cancer pain condition, IC patients already have a difficult time obtaining pain meds. IC doctors do not have time nor the inclination to effectively prescribe or monitor the distribution of the opioid class of medication. They often refer their patients to Pain Management Specialists, many who have never heard of IC, who often refuse to treat them. In addition, antidepressants and benzodiazepines are often used to treat both mood and sleeping disorders for IC patients. Additionally, the NIH investigator-initiated research portfolio continues to be an important mechanism for IC researchers to create new avenues for interdisciplinary research.

THE PATIENT PERSPECTIVE

IC is a tough disease to diagnose, and it is one of the most challenging things to deal with, finding a Dr. that specializes in IC that can help diagnose and treat. I can't stress enough how important finding the right Dr. is. IC patients need a Dr. who understands and is willing to go along with them on this long, frustrating, painful and confusing road. I have found strength through having this that I never knew I had, strength to keep going when all treatments so far have failed me.

There are a small number of treatments available for managing IC symptoms, but they only work on a small percentage of patients. I have tried those treatments and some drugs that "might" help. I manage my diet, take lots of supplements and have to see all kinds of Doctors now. I have six! That includes holistic medicine doctors, physical therapists, and acupuncturist. That's along with my regular MD, Urologist and two different gynecologists. This is what my life has become. The life of an IC patient. I deal with one or more symptoms of IC EVERY SINGLE DAY. Some days definitely better than others, but every single day. It affects my life in so many ways. Work, social, travel and my intimate relationships. I never know how I'm going to feel from one day to the next. Anxiety and fear included.—*Anonymous*

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 JOHNSON & JOHNSON

On behalf of Johnson & Johnson's 135,000 global employees, I am pleased to provide written testimony to the House Appropriations Subcommittee on Labor, Health and Human Services, Education and Related Agencies in support of increased funding for the National Institutes of Health (NIH) fiscal year 2020 budget.

Robust funding for NIH is necessary to ensure that the agency has the continued ability to fuel innovation in medical research, improving the trajectory of healthcare in the United States and around the world. This funding request also represents what is required to remain competitive in addressing emerging health threats confronting the United States and to encourage the pursuit of innovative solutions essential in addressing these increasingly complex challenges.

As a physician and scientist, I have dedicated much of my life to translating basic scientific research into medical advances. In my current role as Global Head of Johnson & Johnson External Innovation and as a board member of Research!America, the Nation's largest not-for-profit public education and advocacy alliance, and the American Association for Cancer Research, the Nation's largest and oldest cancer research organization, I am deeply aware of the value of our Nation's investment in research.

In the United States, the majority of medical research into the root causes of disease is publicly funded by the NIH through research grants to more than 2,500 institutions across the country. The invaluable research conducted by NIH-funded investigators represents the building blocks of scientific discovery, enabling healthcare companies to expand upon this research to transform scientific findings into the breakthrough healthcare products of tomorrow. Furthermore, NIH research often makes possible the business case for the enormous, at-risk investment of the private funding and effort it requires to discover, develop and guide an important new medical treatment through the regulatory process and to patients in need.

At Johnson & Johnson, we are committed to creating life-enhancing innovations and to producing value through partnerships that will profoundly change the trajectory of health for humanity. To that end, in 2018 Johnson & Johnson invested nearly $10.8 billion in research and development across our pharmaceutical, consumer and medical device companies. Our teams of scientists work tirelessly to accelerate the translation of scientific discoveries into meaningful solutions for patients in need. Much of our work, and that of scientists across the industry, would not be possible without the constant progression of the understanding of underlying disease biology—precisely the type of research funded by the NIH.

In addition, Johnson & Johnson recognizes the crucial importance of early-stage companies and the critical role NIH plays in supporting these small businesses through Small Business Innovation Research (SBIR) and Small Business Technology Transfer (STTR) funding. At the Johnson & Johnson Innovation—JLABS incubator sites, we support the life sciences ecosystem by helping entrepreneurs and scientists realize their dreams of creating healthcare solutions that improve lives by identifying and nurturing highly innovative ideas in areas of potentially disruptive, cutting-edge research, which may lead to novel platforms, products or technologies. These are advances that the scientific community could only imagine several years ago, yet they are becoming a reality today through the support of public-private partnerships like these.

The work of the NIH is tied not only to innovation and the vitality of the life sciences, but also to the health of our national economy. NIH is the lifeblood of basic research for America, and is also an incredible economic engine. In fiscal year 2018, NIH research funding directly and indirectly supported over 433,000 jobs and spurred nearly $74 billion in new economic activity. Moreover, the pace of medical research must keep up with the aging of our population. There is an urgent need, both on the individual and socioeconomic level, for strategies to prevent illnesses associated with aging or lifestyle. Diseases such as Alzheimer's, ALS, diabetes, cancer and heart disease threaten to overwhelm our healthcare system in a matter of years with enormous costs of care if we do not find ways to prevent, intercept, treat or cure them.

Investments in medical research at the end of the 20th century by the Federal Government and private life sciences companies, combined with the work of industry and NIH-funded investigators across the country, have produced fundamental scientific advances, vast new datasets and increasingly sophisticated areas of scientific research. As the NIH is working on projects in areas like precision medicine, gene therapy and vaccines to prevent infectious diseases like Ebola, pandemic influenza and HIV, there has never been a more critical and promising time to work in medical research.

Johnson & Johnson believes that fully and consistently funding the NIH represents a commitment to fueling innovation in medical research. It is also a commitment to our communities by advancing science to match medical need, to our current and future generations of scientists by stimulating the life sciences ecosystem, and to the prosperity of our Nation as a worldwide leader in medical research. Sustainable, robust investment is needed to strengthen this research and to realize its benefits for improving people's lives and reducing the burden and associated costs of today's major diseases in the United States and around the world.

[This statement was submitted by William N. Hait, MD, PhD, Global Head, Johnson & Johnson External Innovation.]

PREPARED STATEMENT OF LEARN

The LEARN Coalition (LEARN) would like to thank the 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 2020 funding. LEARN consists of 40 leading research colleges of education across the country which support critical investments in research aimed at advancing the scientific understanding of learning and development. We advocate for greater funding for these priorities across all Federal agencies, including the Institute of Education Sciences (IES), the National Institute of Child Health and Human Development (NICHD), and the National Institute of Mental Health (NIMH).

LEARN urges the subcommittee to make significant investments in key education research programs as part of the fiscal year 2020 appropriations process. These investments are critical if we are to advance the knowledge and practice needed by early childhood, K12 and postsecondary education in our country. We applaud and are encouraged by the significant increases provided by the House Subcommittee on Labor, Health and Human Services, Education and Related Agencies (L–HHS–ED) for these initiatives and urge additional support for critical research programs. Specifically LEARN is requesting $670 million for IES. Within IES, LEARN would recommend $210 million for the Research, Development and Dissemination (R, D and D) line item and $61 million for the National Center for Special Education Research (NCSER). At the National Institutes of Health, we would urge the Subcommittee to provide $1.606 billion and $1.994 billion for NICHD and NIMH respectively.

In addition to our focus on these individual programs, we would be remiss if we did not highlight the importance of the initial work to raise non-defense discretionary (NDD) funding for fiscal year 2020 and fiscal year 2021. As you know, NDD funding would be cut by $55 billion compared to fiscal year 2019 spending levels under the Budget Control Act. We hope this early work by the leaders of the House Budget and Appropriations Committees brings about an eventual agreement by the House, Senate and Administration to increase NDD spending over fiscal year 2019 levels. Absent a bipartisan agreement to increase the non-defense discretionary spending caps, we fear investments in education research would face crippling cuts. Such an agreement would allow for significant investments in education.

While advocating for these programmatic and budget cap increases, we also want to provide the Subcommittee with a real-world picture of the impact of education research funding. Recent IES and other agency funding for education research has produced critical gains in knowledge and understanding of evidence-based practice. Examples of the impact of these dollars include the development and adoption of a statewide approach to math instruction in Florida that has also been adopted by other States and localities, both urban and rural. This curriculum allows students to receive specialized math instruction through a teacher and teaching style with which they connect. Another effort funded by IES is the implementation of a reading curriculum that has shown such positive results for young children that it is now being adopted as a statewide literacy approach by a State legislature. Lastly, NCSER funding has helped lead to the adoption of positive behavior intervention and supports, a behavior management approach that is designed to help children with disabilities and others reach their academic potential without the disruption that behavior issues can cause.

With respect to our funding recommendations, our priority is an increase for IES and the R, D and D and NCSER line items. As the primary Federal Agency charged with supporting research for education practice and policy, IES is essential to developing a comprehensive, reliable evidence base, and ensuring that teaching and learning practices are grounded in scientifically valid research. Increased funding for education research is vital to the implementation of major Federal education programs funded under the Elementary and Secondary Education Act, the Individuals with Disabilities Education Act and the Higher Education Act, as all of these statutes require a focus on the use of evidence-based approaches.

With the importance of developing reliable knowledge and evidence-based practices, LEARN is requesting $670 million for IES overall and $210 million for the Research, Development, and Dissemination line item within IES, in order to keep up with growth and inflation. The funding for research in special education, through the National Center for Special Education Research (NCSER), also should be increased by $5 million, to $61 million, still well below its fiscal year 2010 historically high level of $71.1 million. These increases are critically needed as only one out of every 10 applications are funded by IES, due to budget constraints, presenting lost opportunities to further strengthen evidence-based practice across the education spectrum.

NICHD and NIMH also fund critical education research efforts. NICHD is essential to education research as it examines brain functions and the impact of different educational services on learning and development. LEARN supports a similar percentage increase in NICHD funding to our request for IES—in line with growth and inflation—to bring the total to $1.606 billion. This increase will ensure that researchers can build on the knowledge already gained, evaluate what works best in treating developmental disorders, and develop new research-based strategies to improve student's learning and development.

Additionally, LEARN supports a similar percentage increase in funding for NIMH over fiscal year 2019 enacted levels, bringing the total funding to $1.994 billion. This increase will help further understanding of the behavioral, biological, and environmental mechanisms necessary for developing interventions to reduce the burden of mental and behavioral disorders and optimizing learning and development.

Thank you for the opportunity to submit testimony urging increases for IES, NICHD and NIMH. LEARN happy to respond to any questions that result from your review of this testimony.

The Members of LEARN are:

Boston University—Wheelock College of Education and Human Development
Boston College—Lynch School of Education
Columbia University—Teachers College
Indiana University—School of Education
Iowa State University—College of Human Sciences
Georgia State University—College of Education & Human Development
John Hopkins University—School of Education
Louisiana State University—College of Human Sciences and Education
North Carolina State University—College of Education
Oklahoma University—Jeannine Rainbolt College of Education
Purdue University—College of Education
Penn State University—College of Education
Syracuse University—School of Education
Rutgers University—Graduate School of Education
Texas A&M University—College of Education and Human Development
The Ohio State University—College of Education and Human Ecology
University of Arizona—School of Education
University of Alabama—College of Education
University of California—Santa Barbara Gevirtz Graduate School of Education
University of Central Florida College of Community Innovation and Education
University of Connecticut—Neag School of Education
University of Florida—College of Education
University of Georgia—School of Education
University of Houston—College of Education
University of Illinois Urbana—Champaign College of Education
University of Kansas—School of Education
University of Kentucky—School of Education
University of Maryland College Park—College of Education
University of Minnesota—College of Education and Human Development
University of Missouri—College of Education
University of North Carolina—School of Education
University of Oregon—College of Education
University of Pittsburgh—School of Education
University of Southern California—Rossier School of Education
University of South Carolina—College of Education
University of South Dakota—School of Education
University of Vermont—College of Education and Social Services
Vanderbilt University—Peabody College of Education and Human Development

Virginia Commonwealth University—School of Education
University of Wisconsin- Madison—School of Education

PREPARED STATEMENT OF THE LEUKEMIA & LYMPHOMA SOCIETY

The Leukemia & Lymphoma Society (LLS) appreciates the opportunity to comment on the fiscal year 2020 appropriations for the National Institutes of Health (NIH) and the National Cancer Institute (NCI). LLS applauds the Committee for its consistent leadership in supporting biomedical research and urges Congress to provide at least $41.584 billion for the National Institutes of Health and at least $6.522 billion for the National Cancer Institute, including $30 million to implement the Childhood Cancer Survivorship, Treatment, Access, and Research (STAR) Act (Public Law 115–180) and at least $50 million to implement the childhood cancer research initiative outlined in the President's fiscal year 2020 budget proposal.

LLS is the world's largest voluntary health organization dedicated to fighting blood cancer. Each year, over 170,000 Americans are newly diagnosed with blood cancers, accounting for nearly 10 percent of all newly diagnosed cancers in the United States. The mission of LLS is to find cures for leukemia, lymphoma, Hodgkin's disease and myeloma, and improve the quality of life of patients and their families. LLS is also committed to ensuring that blood cancer patients have sustainable access to quality, affordable, coordinated healthcare. Since our founding in 1949, LLS has invested more than $1.2 billion in groundbreaking research in hematologic disease, funding nearly all of today's most promising advances. LLS is also the leading source of free, highly specialized blood cancer information, education and support for patients, survivors, families and healthcare professionals, responding to over 1,500 inquiries each month.

SUPPORTING GROUNDBREAKING ADVANCES IN BLOOD CANCER TREATMENTS

As an organization that has funded more than $1.2 billion in cancer research since its founding, LLS knows firsthand how crucial sustained investments in biomedical research are to tackling disease. The reach of NIH and NCI extend beyond the NIH campus in Bethesda, Maryland, supporting research at universities, academic centers and medical centers across the United States.

The importance of this work cannot be overstated, as consistent investments in biomedical research are leading to scientific advances in precision medicine, genomics and immunotherapy, which continue to transform the landscape of cancer care. In 2017 and 2018, the FDA approved an unprecedented 39 blood cancer medications due to groundbreaking research and innovation. This boom in blood cancer drugs is expected to continue.

While incredible progress has been made, particularly in recent years, challenges in treating blood cancer remain. More than 1.3 million Americans are currently living with or in remission from a blood cancer, and every three minutes, someone in the United States is diagnosed with a blood cancer. However, more than one-third of blood cancer patients still do not survive 5 years after their initial diagnosis. For the last 50 years, every major medical breakthrough in cancer can be traced back to NIH and NCI; LLS and the cancer community continue to rely on the vision and leadership of the NIH and NCI to fuel further progress in treating blood cancer.

NIH AND NCI AS PARTNERS IN RESEARCH INNOVATION

LLS's research portfolio drives research in areas of unmet medical need and strives to bridge the gap between academic discovery and drug development. We are deeply committed to taking a leading role in the development of precision medicine-based treatments. LLS launched a master protocol in 2016 for biomarker-based treatment of acute myeloid leukemia (AML). This master protocol—the Beat AML Master(r) Trial—is a multi-drug, multi-site precision medicine approach testing several novel targeted therapies.

LLS recognized an acute research need in AML patients; AML is a complex grouping of more than ten different prominent subtypes of blood cancer, and many other rare mutations. Each year in the United States, approximately 21,000 patients are diagnosed with AML and more than 10,000 lives are lost to this disease. Through the Beat AML Master(r) Trial, for which LLS holds the U.S. investigational new drug application (IND), LLS has successfully collaborated with multiple medical institutions, pharmaceutical companies and the FDA to launch the first-ever precision medicine clinical trial in a blood cancer. Under our master protocol—a trial structure that allows testing of more than one therapy under an 'umbrella' protocol—all newly diagnosed AML patients age 60 years and older are eligible for participation.

Each patient who consents receives a genomic screening upon diagnosis, and a sample from a bone marrow biopsy is sent for a rapid analysis by a genomic provider. Based on the results, the patient is assigned to receive personalized therapy on one of several sub-studies to the protocol, each with its own consent form and with arm-specific clinical/correlative endpoints, but all sharing the goal of improving outcomes in patients.

The trial currently includes more than 10 active treatment arms, each based on the most prominent subsets of AML and testing one of the investigational therapies. As with any research endeavor, the goal is to develop and accelerate treatments and cures for patients. In this case, our hope is that one or more innovative treatments will emerge from this trial, which will advance cures for AML patients.

Bolstered by the success of the adult Beat AML Master(r) Trial, LLS is setting its sights on changing the paradigm for drug development in children with acute leukemia. LLS plans to launch a new pediatric clinical trial that looks to establish the infrastructure to rapidly evaluate novel targeted therapies or novel combinations in children and young adults with leukemia, with the ultimate goal of speeding approval of new agents. This trial—part of the broader LLS Children's Initiative—will utilize key aspects of NCI's infrastructure and resources, which will be critical for the success of this effort. Leadership from NCI will also serve on the Scientific Steering Committee for LLS's trial, providing important expertise and guidance to our efforts.

The LLS pediatric trial seeks to be the leukemia complement to the NCI Pediatric MATCH program, which takes a precision medicine approach for patients with solid tumors that are not responding to treatment. NIH and NCI have been invaluable partners in this endeavor, and LLS plans to launch this new precision medicine clinical trial for children by the end of 2019.

REQUESTS FOR FISCAL YEAR 2020 APPROPRIATIONS

Based on the vital importance of scientific research, LLS requests the following appropriations for fiscal year 2020:

National Institutes of Health (NIH).—To continue the progress that has led to medical breakthroughs for blood cancer patients, NIH needs an increased, sustainable Federal investment. LLS urges Congress to provide at least $41.584 billion for the National Institutes of Health in fiscal year 2020, a $2.5 billion increase over fiscal year 2019.

National Cancer Institute (NCI).—Despite its growing budget over recent years, NCI's resources are being stretched by an increasing number of funding applications and other priorities. The number of proposals submitted to NCI increased 46 percent from fiscal year 2013 to fiscal year 2018, far exceeding the proposal submission growth seen by NIH as a whole, which rose by 11 percent in that same timeframe. To meet its obligations while continuing to support the most promising research, last year, NCI imposed a 5 percent operating budget cut across the Institute.

Each fiscal year, NCI is required to submit to Congress a Professional Judgment Budget to outline the optimum funding needed to make the most rapid progress against cancer. For fiscal year 20, the Professional Judgment Budget for the NCI requests a $378 million increase over fiscal year 2019 funding levels. These new resources would be used for initiatives aimed at understanding the mechanisms of cancer, preventing cancer, detecting and diagnosing cancer, treating cancer, advancing public health in cancer and strengthening the cancer research enterprise. Consistent with NCI's fiscal year 2020 Professional Judgment Budget, LLS encourages Congress to provide at least $6.522 billion for the National Cancer Institute in fiscal year 2020.

Childhood Cancer Programs.—The Childhood Cancer Survivorship, Treatment, Access, and Research (STAR) Act, the most comprehensive childhood cancer legislation considered by Congress, was unanimously passed last year. This important legislation, which was fully funded for fiscal year 2019, authorizes $30 million in new resources for the NIH and Centers for Disease Control (CDC) to expand opportunities for childhood cancer research, improve efforts to identify and track childhood cancer incidences and enhance the quality of life for childhood cancer survivors. LLS was also heartened by the Administration's proposal for a $500 million investment in childhood cancer research over the next decade. Within NCI's fiscal year 2020 appropriation, LLS urges Congress to provide $30 million to fully fund the Childhood Cancer STAR Act (Public Law 115–180) and at least $50 million to fully fund the childhood cancer research initiative outlined in the President's fiscal year 2020 budget proposal.

CONCLUSION

LLS appreciates the leadership and support of the Subcommittee and its priority setting activities. We look forward to continuing to work with Congress on policies that advance cures and break down barriers to healthcare access for blood cancer patients and survivors.

PREPARED STATEMENT OF THE LOW INCOME HOME ENERGY ASSISTANCE PROGRAM

The Federal Low Income Home Energy Assistance Program (LIHEAP)[1] is the cornerstone of government efforts to help needy seniors and families stay warm and avoid hypothermia in the winter, as well as stay cool and avoid heat stress (even death) in the summer. LIHEAP is an important safety net program for low-income, unemployed and underemployed families struggling in this economy. LIHEAP has helped approximately 6 million households afford their energy bills in fiscal year 2019.[2] In light of the crucial safety net function of this program in protecting the health and well-being of low-income seniors, consumers with disabilities, and families with very young children, we respectfully request that LIHEAP be funded at no less than $4.7 billion for fiscal year 2020.

THE URGENT NEED FOR ADEQUATE LIHEAP APPROPRIATIONS

Funding LIHEAP at no less than $4.7 billion for the regular program in fiscal year 2020 would restore LIHEAP funding to fiscal year 2011 levels and will help protect the health and well-being of an estimated additional one million fragile households according to the National Energy Assistance Directors' Association.[3]

One indicator of the growing need for energy assistance is the growing number of disconnections. In States like Iowa that track utility credit and collections information, the involuntary disconnection of residential gas and electric customers increased by 123 percent between 1999 and 2018. For the year ending December 1999, there were less than 25,000 involuntary disconnections in Iowa. For the calendar year ending December 2018 the disconnections had more than doubled to well over 55,000. The increase over the long term in disconnection of vital home energy and utility services, as seen in Iowa, may be observed in States around the country that collect and report such information, including Ohio, Pennsylvania, California, and Massachusetts. For very poor, struggling households, LIHEAP helps bring the cost of these essential heating and cooling services within reach for an estimated 6 million low-income households and helps them stay connected.

Energy bills are not affordable for struggling, low-income households. The average LIHEAP household in 2015 devoted over 8 percent of total household income just for home energy services, compared to an average of under 4 percent for all U.S. households. Home energy is also more expensive during prolonged periods of extreme temperatures because households use more fuel to keep the home at safe temperatures. Prolonged colder than normal temperatures, such as the sharp cold wave that resulted in 22 deaths and affected a wide swath of the country January to March 2019[4] can result in an unexpected, increased use of heating fuels. Likewise, prolonged hot temperatures can result in an increased need for air conditioning, particularly for consumers with certain medical conditions.[5]

Yet, struggling low-income households are at risk of disconnection from essential utilities because they do not have the savings or income on hand to afford their energy bills. The Federal Reserve finds that 4 in 10 households report that they would have difficulty with an unexpected expense of $400 and that 3 in 10 households are

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[1] 42 U.S.C. § § 8621 et seq.

[2] Testimony of the National Energy Assistance Directors' Association, House Subcommittee on Labor, Health and Human Services and Education and Related Agencies (April 8, 2019).

[3] Testimony of the National Energy Assistance Directors' Association, House Subcommittee on Labor, Health and Human Services and Education and Related Agencies (April 8, 2019).

[4] See e.g., "Extreme cold in the Midwest led to high power demand and record natural gas demand," U.S. Energy Information Administration, Today in Energy (Feb. 26, 2019) available at https://www.eia.gov/todayinenergy/detail.php?id=38472; "January—February 2019 North American cold wave", https://en.wikipedia.org/wiki/January%E2%80%93February__2019__North__American__cold__wave.

[5] Lynne Page Snyder and Christopher Baker, Affordable Home Energy and Health: Making the Connections, AARP Public Policy Institute (June 2010) at pp.10–11, available at https://www.aarp.org/money/low-income-assistance/info-06–2010/2010-05-consumer.html.

either unable to pay their bills or are a modest financial setback from hardship.[6] A growing body of research is documenting the rise in household income volatility (the dramatic fluctuation of income over time) and the impacts on household well-being.[7] Approximately one-third of households experience income volatility[8] and irregular work schedules were the leading cause of volatility.[9] When income is hard to predict from week-to-week and month-to-month, paying for necessities such utility service can be difficult, if not impossible without help from programs like LIHEAP. Households experiencing income volatility tend to turn to more expensive alternative financial services products such as payday loans.[10] Analysis of material hardship for low and moderate income consumers experiencing income volatility found much higher rates of skipped bills, skipped medical care, skipped housing payments and food insecurity.[11]

LIHEAP protects the health and safety of the frail elderly, the very young and those with chronic health conditions, such as diabetes, that increase susceptibility to temperature extremes. LIHEAP assistance also helps keep families together by keeping homes habitable during the bitter cold winter and sweltering summers.

LIHEAP Is a Critical Safety Net Program for the Elderly, the Disabled and Households with Young Children

Dire Choices and Dire Consequences: Recent national studies have documented the dire choices low-income households face when energy bills are unaffordable. Because adequate heating and cooling are tied to the habitability of the home, low-income families will go to great lengths to pay their energy bills. According to the US Energy Information Agency (EIA), one in three households face challenges meeting energy needs, with over 20 percent forgoing basic necessities to pay their energy bills, over 10 percent report keeping their home at unsafe temperatures and almost 15 percent received a disconnection notice.[12] EIA's analysis is consistent with other studies showing that low-income households faced with unaffordable energy bills cut back on necessities such as food, medicine and medical care.[13] The U.S. Department of Agriculture has documented the connection between low-income households, especially those with elderly persons, experiencing very low food security and heating

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[6] Board of Governors of the Federal Reserve, Report on the Economic Well-Being of U.S. Households in 2018 (May 2019) at p.21, available at https://www.Federalreserve.gov/consumerscommunities/files/2018-report-economic-well-being-us-households-201905.pdf.

[7] See e.g., Federal Reserve Survey of Household Economics and Decisionmaking reports available at https://www.Federalreserve.gov/consumerscommunities/shed.htm; The Aspen Institute Expanding Prosperity Impact Collaborative (EPIC) series on the issue of income volatility available at http://www.aspenepic.org/epic-issues/income-volatility/; Pew Charitable Trusts, How Income Volatility Interacts with American Families; Financial Security (March 9, 2017) available at https://www.pewtrusts.org/en/research-and-analysis/issue-briefs/2017/03/how-income-volatility-interacts-with-american-families-financial-security.

[8] Daniel Schneider and Kristen Harknett, Income Volatility in the Service Sector: Contours, Causes, and Consequences (July 2017) at p.3, available at http://www.aspenepic.org/epic-issues/income-volatility/issue-briefs-what-we-know/issue-brief-income-volatility-service-sector/; Board of Governors of the Federal Reserve, Report on the Economic Well-Being of U.S. Households in 2018 (May 2019) at p.2, available at https://www.Federalreserve.gov/consumerscommunities/files/2018-report-economic-well-being-us-households-201905.pdf.

[9] "Income Volatility: A Primer (May 1, 2016) The Aspin Institute Financial Security Program and EPIC at p.5, available at https://www.aspeninstitute.org/publications/income-volatility-a-primer/; Daniel Schneider and Kristen Harknett, Income Volatility in the Service Sector: Contours, Causes and Consequences (July 2017) at p.3, available at http://www.aspenepic.org/epic-issues/income-volatility/issue-briefs-what-we-know/issue-brief-income-volatility-service-sector/,
Asset Funders Network, Income Volatility: Why it Destabilizes Working Families and How Philanthropy Can Make a Difference at p.6, available at https://assetfunders.org/resource/afn-income-volatility-2017/.

[10] Daniel Schneider and Kristen Harknett, Income Volatility in the Service Sector: Contours, Causes and Consequences (July 2017) at p. 9, available at http://www.aspenepic.org/epic-issues/income-volatility/issue-briefs-what-we-know/issue-brief-income-volatility-service-sector/(almost a quarter of consumers reporting week-to-week volatility report using payday lenders).

[11] Stephen Roll, David S. Mitchell, Krista Holub et al., Responses to and Repercussions from Income Volatility in Low- and Moderate-Income Households: Results from a National Survey, Aspen Institute EPIC, Center for Social Development, Intuit Tax & Financial Center (Dec. 2–17) at pp 6–7, available at https://www.aspeninstitute.org/publications/responses-repercussions-income-volatility-low-moderate-income-households-results-national-survey/.

[12] "One in three U.S. households faces a challenge in meeting energy needs," US Energy Information Administration, Today in Energy (Sept. 19, 2018) available at https://www.eia.gov/todayinenergy/detail.php?id=37072.

[13] See e.g., National Energy Assistance Directors' Association, 2018 National Energy Assistance Survey, Tables in section IV, F and G (Dec. 2018)(to pay their energy bills, 32 percent of LIHEAP recipients went without food, 41 percent went without medical or dental care, 31 percent did not fill or took less than the full dose of a prescribed medicine, 13 percent got a payday loan). Available at http://neada.org/wp-content/uploads/2015/03/liheapsurvey2018.pdf.

and cooling seasons when energy bills are high.[14] A pediatric study in Boston documented an increase in the number of extremely low weight children, age 6 to 24 months, in the 3 months following the coldest months, when compared to the rest of the year.[15] It is shocking that in this wealthy Nation, so many face heat-or-eat choices where families go without food during the winter to pay their heating bills, and their children fail to thrive and grow. A 2007 Colorado study found that the second leading cause of homelessness for families with children is the inability to pay for home energy.[16]

When people are unable to afford paying their home energy bills, dangerous and even fatal results occur. In the winter, families resort to using unsafe heating sources, such as space heaters, ovens and burners, all of which are fire hazards. Space heaters pose 3 to 4 times more risk for fire and 18 to 25 times more risk for death than central heating. In 2007, space heaters accounted for 17 percent of home fires and 20 percent of home fire deaths.[17] In the summer, the inability to keep the home cool can be lethal, especially to seniors. According to the CDC, older adults, young children and persons with chronic medical conditions are particularly susceptible to heat-related illness and are at a high risk of heat-related death. The CDC reports that 3,442 deaths resulted from exposure to extreme heat during 1999–2003.[18] The CDC also notes that air-conditioning is the number one protective factor against heat-related illness and death.[19] LIHEAP assistance helps these vulnerable seniors, young children and medically vulnerable persons keep their homes at safe temperatures during the winter and summer and also funds low-income weatherization work to make homes more energy efficient.

LIHEAP is an administratively efficient and effective targeted health and safety program that works to bring fuel costs within a manageable range for vulnerable low-income seniors, the disabled and families with young children. We respectfully request that LIHEAP be funded at no less than $4.7 billion in fiscal year 2020.

[This statement was submitted by Olivia Wein, Staff Attorney, National Consumer Law Center.]

PREPARED STATEMENT OF THE LYMPHATIC EDUCATION & RESEARCH NETWORK

KEY RECOMMENDATIONS

- —Provide the National Institutes of Health (NIH) with $41.6 billion for fiscal year 2020 and advance lymphatic disease research by expanding resources and encouraging better coordination among relevant institutes and centers
- —Establish a National Commission on Lymphatic Disease Research at the NIH to identify emerging opportunities, challenges, gaps, structural changes, and recommendations on lymphatic disease research
- —Provide the Centers for Disease Control and Prevention (CDC) with $7.8 billion for fiscal year 2020 and enable programmatic activity on lymphatic disease education and public awareness

Chairman Blunt, Ranking Member Murray, and distinguished members of the Subcommittee, thank you for the opportunity to testify before you as you consider fiscal year 2020 appropriations for the National Institutes of Health (NIH) and the Centers for Disease Control and Prevention (CDC).

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[14] Mark Nord and Linda S. Kantor, Seasonal Variation in Food Insecurity Is Associated with Heating and Cooling Costs Among Low-Income Elderly Americans, The Journal of Nutrition, 136 (Nov. 2006) 2939–2944.

[15] Deborah A. Frank, MD et al., Heat or Eat: The Low Income Home Energy Assistance Program and Nutritional and Health Risks Among Children Less Than 3 years of Age, AAP Pediatrics v.118, no. 5 (Nov. 2006) e1293-e1302. See also, Child Health Impact Working Group, Unhealthy Consequences: Energy Costs and Child Health: A Child Health Impact Assessment Of Energy Costs And The Low Income Home Energy Assistance Program (Boston: Nov. 2006) and the Testimony of Dr. Frank Before the Senate Committee on Health, Education, Labor and Pensions Subcommittee on Children and Families (March 5, 2008).

[16] Colorado Interagency Council on Homelessness, Colorado Statewide Homeless Count Summer, 2006, research conducted by University of Colorado at Denver and Health Sciences Center (Feb. 2007).

[17] John R. Hall, Jr., Home Fires Involving Heating Equipment (Jan. 2010) at ix and 33. Also, 40 percent of home space heater fires involve devices coded as stoves.

[18] CDC, “Heat-Related Deaths—United States, 1999–2003” MMWR Weekly, July 28, 2006.

[19] CDC, “Extreme Heat: A Prevention Guide to Promote Your Personal Health and Safety” available at http://emergency.cdc.gov/disasters/extremeheat/heat__guide.asp.

My name is Kathy Bates, and I have lymphedema. I was diagnosed with breast cancer almost 7 years ago and had a double mastectomy. My surgeons felt it necessary to remove 19 lymph nodes from my left armpit and 3 from my right. I am profoundly grateful to the doctors who cured me of cancer, but the cost of that cure means I am forced to live with this incurable disease for the rest of my life.

ABOUT LE&RN

I serve as the National Spokesperson for the Lymphatic Education & Research Network, also known as LE&RN. Our mission is to fight lymphatic diseases and lymphedema through education, research and advocacy. With chapters throughout the world, LE&RN seeks to accelerate the prevention, treatment and cure of these diseases while bringing patients and medical professionals together to address the unmet needs surrounding lymphatic diseases.

ABOUT LYMPHEDEMA AND LYMPHATIC DISEASES

The lymphatic system is a circulatory system that is critical to immune function and good health. When it is compromised and lymph flow is restricted, the physical impact to patients can be devastating, life altering, and can lead to shortened lifespan. Lymphedema (LE) is one such lymphatic disease. LE is a chronic, debilitating, and incurable swelling that can be a result of cancer treatment, inherited or genetic causes, damage to the lymphatic system from surgery or an accident, or from parasites as in lymphatic filariasis. Stanford University estimates that up to 10 million Americans have lymphedema. This represents more Americans than those living with AIDS, Multiple Sclerosis, Parkinson's disease, Muscular Dystrophy and ALS—combined. The World Health Organization puts the global number of people with this disease at 250 million. There is no cure. There is no approved drug therapy. And there are currently only three drug studies worldwide seeking a treatment. Psychosocially bruised by a disease that leaves us deformed, we do our best to hide our lymphedema. We are currently isolated and alone.

Lymphedema is an equal opportunity disease, affecting women, men and children alike. Many are born with congenital or hereditary lymphedema. Others, like our veterans, get the disease as a result of physical trauma, bacterial infection, or as result of exposure to burn pits. Like seven million other Americans, I developed lymphedema after I was treated for cancer. In my case, within a week of having a double mastectomy, I began to feel the symptoms of the disease: chronic swelling in my arms, pain, and loss of mobility. I learned that I could now expect a lifetime of severe bacterial infections called cellulitis, which can prove fatal. I learned that those of us with LE faced a lifetime of time-consuming daily care regimens. These include manual lymph drainage massage, wrapping oneself in compression garments and using a pneumatic pump to control the swelling. Forever. Compression garments aren't even covered by Medicare. We are working to expand access through the Lymphedema Treatment Act, and we are hopeful this bill will pass this year. But it is clear that this community deserves more options.

Lymphedema is an ignored disease. A study concluded that physicians are currently getting an average of only 15–30 minutes of study on the lymphatic system in their entire medical training. This leaves them ill-prepared to diagnose the disease. Misdiagnosis leads to improper treatment. Those who are diagnosed find it difficult to find certified lymphedema therapists. Few medical centers exist that are prepared to address lymphatic diseases. Surgeons are experimenting with treatment that could alter the course of the disease. However, the necessary basic research is not being done to inform their procedures. And currently, Medicare and Medicaid do not cover some of the basic treatment needs of these patients—such as compression garments, which we must all wear daily.

FISCAL YEAR 2020 APPROPRIATIONS RECOMMENDATIONS

It is time for a challenge worthy of our great country. We ask that within 20 years, we will make lymphedema a truly treatable disease. To reach this goal will require a commitment to important medical research. LE&RN joins the broader medical research community in thanking Congress for continuing to provide the National Institutes of Health with proportional and sustainable funding increases over the past several fiscal years, and we ask you all to continue to prioritize these activities by providing at least a $2.5 billion funding increase for fiscal year 2020 to bring NIH's budget up to $41.6 billion.

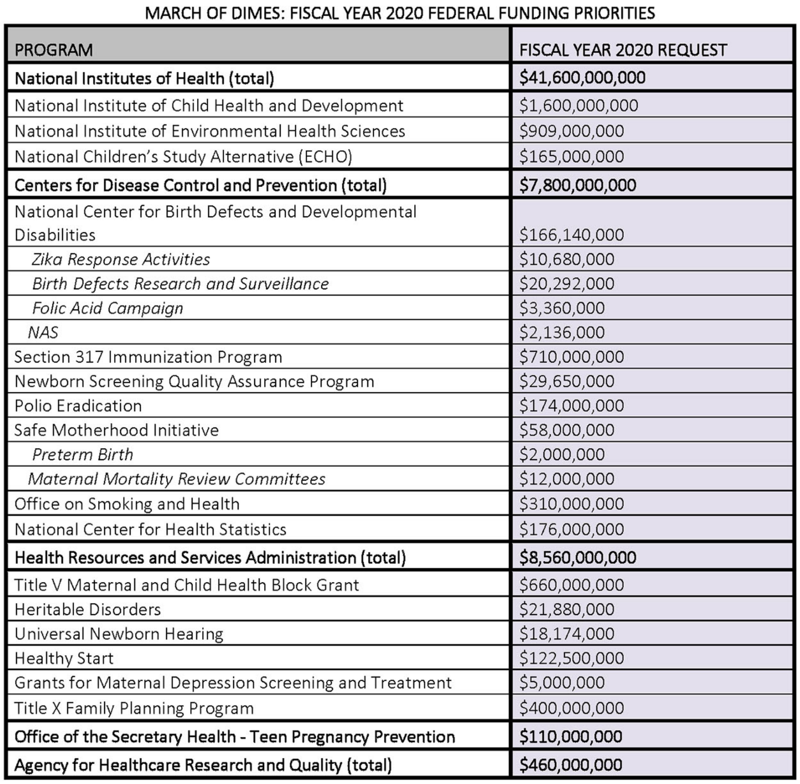
We also urge the Subcommittee to work to expand and advance the lymphatic disease portfolio at the NIH. In late 2015, the NIH hosted a Lymphatic Symposium, where experts in the field identified a scientific roadmap that could build the research portfolio up to a level of at least $70 million annually over subsequent years by funding meritorious grants on critical topics. In an effort to further support and enhance emerging lymphedema and lymphatic disease research activities, we ask the Subcommittee to encourage further collaboration among relevant institutes and centers conducting research in this area. We also call on the Subcommittee to work with your colleagues to establish a National Commission on Lymphatic Disease Research, which can thoroughly examine the portfolio and make recommendations on how best to advance this emerging scientific area under NIH's current structure. Currently, the National Institutes of Health spends approximately $25 million annually on lymphatic research, and only $5 million of this is dedicated to clinical lymphedema research. Experts state with confidence that there is no other disease affecting more Americans that receives so little attention. It must also be noted that study of the lymphatic system is poised to bring miracles for a host of diseases that are part of the lymphatic continuum: obesity, heart disease, diabetes, Rheumatoid arthritis, cancer metastasis, AIDS, Crohn's disease, lipedema, and a host of other diseases. Recent research discovered lymphatics surrounding the brain, which now has us studying its impact on Alzheimer's disease and multiple sclerosis.

LE&RN also joins the public health community in asking Congress to provide the Centers for Disease Control and Prevention (CDC) with $7.8 billion through fiscal year 2020 and to establish funding to increase awareness, education, and surveillance of lymphatic diseases. The CDC's National Center for Chronic Disease Prevention and Public Health Promotion has programs dedicated to improving surveillance, physician education, and public awareness for several chronic diseases. We encourage the Subcommittee to establish merit-based programmatic activity in this area that will allow CDC to work with stakeholder organizations to expand important initiatives on lymphedema and lymphatic diseases. Formal study of the lymphatic system and of lymphatic diseases is virtually nonexistent in the current curricula of U.S. medical schools, and misinformation routinely leads to misdiagnosis and under-treatment. This delay and misdirection of treatment results in irreparable physical and psychosocial harm to patients suffering from these already debilitating diseases. CDC can help to address this lack of public and provider awareness.

Thank you for the opportunity to testify before you. LE&RN looks forward to working with you all to advance medical research and public health activities that will improve patient outcomes for the members of our community suffering from these debilitating diseases.

[This statement was submitted by Kathy Bates, National Spokesperson, Lymphatic Education & Research Network.]

PREPARED STATEMENT OF MARCH OF DIMES



MARCH OF DIMES: FISCAL YEAR 2020 FEDERAL FUNDING PRIORITIES

PROGRAM	FISCAL YEAR 2020 REQUEST
National Institutes of Health (total)	**$41,600,000,000**
National Institute of Child Health and Development	$1,600,000,000
National Institute of Environmental Health Sciences	$909,000,000
National Children's Study Alternative (ECHO)	$165,000,000
Centers for Disease Control and Prevention (total)	**$7,800,000,000**
National Center for Birth Defects and Developmental Disabilities	$166,140,000
Zika Response Activities	$10,680,000
Birth Defects Research and Surveillance	$20,292,000
Folic Acid Campaign	$3,360,000
NAS	$2,136,000
Section 317 Immunization Program	$710,000,000
Newborn Screening Quality Assurance Program	$29,650,000
Polio Eradication	$174,000,000
Safe Motherhood Initiative	$58,000,000
Preterm Birth	$2,000,000
Maternal Mortality Review Committees	$12,000,000
Office on Smoking and Health	$310,000,000
National Center for Health Statistics	$176,000,000
Health Resources and Services Administration (total)	**$8,560,000,000**
Title V Maternal and Child Health Block Grant	$660,000,000
Heritable Disorders	$21,880,000
Universal Newborn Hearing	$18,174,000
Healthy Start	$122,500,000
Grants for Maternal Depression Screening and Treatment	$5,000,000
Title X Family Planning Program	$400,000,000
Office of the Secretary Health - Teen Pregnancy Prevention	**$110,000,000**
Agency for Healthcare Research and Quality (total)	**$460,000,000**

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 2020 appropriations for the Department of Health and Human Services (HHS). March of Dimes leads the fight for the health of all mothers and infants through our research, community services, education, and advocacy. Our organization recommends the aforementioned funding levels for programs and initiatives that are essential investments in maternal and child health.

Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD):

March of Dimes recommends that Congress provide at least $1.6 billion for NICHD's groundbreaking biomedical research activities in fiscal year 2020. Increased funding will allow NICHD to sustain vital research on preterm birth, maternal mortality, maternal substance use, prenatal substance exposure and related issues through extramural grants, Maternal-Fetal Medicine Units, the Neonatal Research Network and the intramural research program. March of Dimes is strongly supportive of NICHD's efforts to expand research identifying safe and effective therapies for pregnant and lactating women. The Task Force on Research Specific to Pregnant and Lactating Women (PRGLAC) laid the foundation for this important work by releasing recommendations in September 2018 as mandated by Congress in the 21st Century Cures Act (Public Law 114–255). March of Dimes is encouraged that NIH has renewed PRGLAC for an additional 2 years to continue its essential work. Funding for NICHD will also support important research to address gaps in our understanding of the best way to treat mothers with opioid use disorder and the long-term impact of opioid exposure in utero as well as to determine the health risks that Zika virus infection poses to pregnant women and their developing fetuses.

Title V Maternal and Child Health Block Grant Program:

March of Dimes recommends funding the Title V Maternal and Child Health Block Grant Program (Title V Block Grant) at $698 million. States, territories and other jurisdictions use Title V Block Grant funds to support their most pressing maternal and child health needs. We thank you for new funds made available in fiscal year 2019 to intensify State efforts to prevent maternal deaths and severe maternal morbidity. States are using this new investment to support maternal mortality review committees, implement the Alliance for Innovation on Maternal Health program, and continue State Maternal Health Innovation Grants. We urge the Committee to increase funding for the Title V Block Grant in fiscal year 2020 to allow States to address maternal mortality while maintaining and expanding its work to improve maternal and child health across the Nation.

Safe Motherhood Initiative:

The mission of the Safe Motherhood Initiative at the CDC's National Center for Chronic Disease Prevention and Health Promotion is to promote optimal reproductive and infant health. March of Dimes recommends funding of $58 million for the Safe Motherhood program, level with the amount provided in fiscal year 2019. The money would be used to sustain CDC's efforts to address the Nation's alarming number of maternal deaths by supporting State-based maternal mortality review committees. March of Dimes also strongly urges maintenance of the preterm birth sub-line at $2 million, as authorized in the PREEMIE Reauthorization Act of 2018 (Public Law 115–328), to maintain ongoing and essential preterm birth research at CDC. This work is helping prevent preterm birth and improve outcomes for the one in 10 babies born too soon in the United States.

National Center on Birth Defects and Developmental Disabilities (NCBDDD):

NCBDDD is the lead Federal agency tasked with supporting vital surveillance, research, and prevention activities on birth defects and developmental disabilities. For fiscal year 2020, March of Dimes urges the Committee to provide at least $166.14 million for NCBDDD and apply this increase across the full range of NCBDDD activities. This increase aligns with March of Dimes' request to increase funding for the CDC by 22 percent by fiscal year 2022. We also urge the Committee to continue support for two new NCBDDD activities funded in fiscal year 2019, the Surveillance for Emerging Threats to Mothers and Babies Initiative and work to improve neonatal abstinence syndrome (NAS) surveillance. The Emerging Threats Initiative enables select States and jurisdictions to continue important work begun during the Zika virus response to identify and address new threats to mothers and infants. NCBDDD's efforts to improve NAS surveillance are vital to helping us understand and address the opioid epidemic's short- and long-term impact on infants.

Newborn Screening: March of Dimes urges funding of $29.8 million for CDC's Newborn Screening Quality Assurance Program (NSQAP) and $21.9 million for the Health Resources and Services Administration's 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 Disorders in Newborns and Children (ACHDNC), which provides recommendations to the HHS Secretary for conditions to be included in the Recommended Uniform Screening Panel (RUSP). In recent years, the ACHDNC has added four new conditions to the RUSP, bringing the total number of recommended screens to 35. 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.

Grants for Maternal Depression Screening and Treatment: Research shows that up to one in seven pregnant women or new mothers experience some sort of maternity-related depression, yet only about 15 percent of those affected receive treatment. The 21st Century Cures Act sought to address this gap by authorizing grants to States to improve screening for and treatment of maternal depression in pregnant and postpartum women. March of Dimes appreciates that Congress provided funding for this innovative grant program in fiscal year 2019 and urges the Committee to make available the full authorized amount of $5 million again in fiscal year 2020.

Funding to Promote Optimal Birth Spacing and Improved Birth Outcomes: Research shows that appropriate birth spacing—waiting at least 18 months between pregnancies—can dramatically reduce the risk of poor birth outcomes. Additionally, we know that the youngest mothers have some of the worst birth outcomes. We can mitigate these risk factors by ensuring women have access to evidence-based counseling and education prior to pregnancy and access to all forms of contraception approved by the Food and Drug Administration. To support these important goals, March of Dimes recommends funding of $400 million for Title X Family Planning Program and $110 million for the Teen Pregnancy Prevention Program administered by the Office of the Assistant Secretary for Health.

CONCLUSION

March of Dimes volunteers and staff look forward to working with appropriators and all of Congress to secure the resources needed to improve our Nation's health. Federal public health programs are essential to preventing preterm birth, ending preventable maternal deaths, and addressing the opioid epidemic's impact on mother, infants and families.

[This statement was submitted by Rahul Gupta, MD, MPH, MBA, FACP, Chief Medical & Health Officer, Senior Vice President, March of Dimes.]

PREPARED STATEMENT OF THE MARFAN FOUNDATION

SUMMARY OF RECOMMENDATIONS FOR FISCAL YEAR 2020

—Provide $41.6 billion for the National Institutes of Health (NIH) and proportional increases across its Institutes and Centers

—Continue expanding heritable connective tissue condition/vascular malformation research supported by NIH with proportional funding increases for the National Heart, Lung, and Blood Institute (NHLBI); National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS); National Eye Institute (NEI); and National Center for Advancing Translational Sciences (NCATS).

Chairman Blunt, Ranking Member Murray and distinguished members of the Subcommittee, thank you for your time and your consideration of the priorities of the community of individuals impacted by Marfan Syndrome, vascular Ehlers-Danlos Syndrome, and Loeys-Dietz Syndrome as you work to craft the fiscal year 2020 L–HHS Appropriations Bill.

ABOUT MARFAN SYNDROME, VASCULAR EHLERS DANLOS, LOEYS-DIETZ SYNDROME, VASCULAR MALFORMATIONS, AND OTHER HERITABLE CONNECTIVE TISSUE DISORDERS

Connective tissue is found throughout the body and heritable connective tissue disorders, like Marfan syndrome, vascular Ehlers-Danlos Syndrome, and Loeys-Dietz Syndrome can affect many different parts of the body. Features of the conditions are most often found in the heart, blood vessels, bones, joints, and eyes. Many of these conditions are genetic and cause issues including the enlargement of the aorta (the main blood vessel that carries blood from the heart to the rest of the body), 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, vascular Ehlers Danlos, Loeys-Dietz syndrome, and related aortic aneurysm syndromes.

—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 condition receives a proper diagnosis, gets the necessary treatment, and lives a long and full life.

CENTERS FOR DISEASE CONTROL AND PREVENTION

People with heritable connective tissue disorders are born with them but features of the conditions are not always present right away. Some people have a lot of features at birth or as young children—including serious conditions like aortic enlargement. Others have fewer features when they are young and don't develop aortic enlargement or other signs of Marfan syndrome, vascular Ehlers Danlos, or Loeys-

Dietz syndrome until they are young adults. Some features of these syndromes, like those affecting the heart and blood vessels, bones or joints, get worse over time. This makes it very important for people with such conditions to receive accurate, early diagnosis and treatment. Without it, they can be at risk for potentially life-threatening complications that could lead to a sudden early death. The earlier some treatments are started, the better the outcomes are likely to be.

Please provide $750,000 for a rare heart disease program that includes enhanced sports screenings at the Centers for Disease Control and Prevention's (CDC). Aortic aneurysm syndrome conditions continue to claim the lives of people across the country, including high school athletes who have not received an appropriate sports physical prior to participation. A CDC program that promotes education and awareness activities would ensure that there is a greater awareness of the increasing number of genetic aortic conditions that affect people from coast-to-coast and ensure that all young athletes are appropriately screened for potentially life-threatening genetic aortic conditions.

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 ACCESS/PATIENT PERSPECTIVE

Other than his height, Nick Vogel, a 6'9" volleyball player from San Diego, did not display easily-detectable characteristics of Marfan syndrome. Intensive screening for the disorder isn't indicated nor affordable for the average 16–18 year old who plays the sport, where being tall is standard. It wasn't until a routine echocardiogram was performed by the USA Volleyball Team's physician that an abnormality was detected in Nick's aorta. Nick received the news while playing for Club Team Friedrichshafen in Germany, and he was then told to stop all strenuous activity immediately.

Genetic sequencing throughout the following weeks would reveal an FBN1 mutation, and Nick subsequently retired from volleyball at the age of 25. Since then, it has become Nick's mission (along with his mother Rita) to raise awareness, to educate, and to support athletes who may be affected by Marfan or related conditions. Without the echocardiogram and subsequent genetic testing, Nick may not have received his diagnosis until he had suffered a potentially life-ending aortic dissection, and by then, it would be too late.

[This statement was submitted by Michael Weamer, President and CEO, The Marfan Foundation.]

PREPARED STATEMENT OF THE MASSACHUSETTS ENERGY DIRECTORS ASSOCIATION

The Massachusetts Energy Directors Association (MEDA) is a State-wide coalition of Energy/Fuel Directors advocating on behalf of the Low Income Home Energy Assistance Program (LIHEAP) recipients within the Commonwealth of Massachusetts.

The program is administered by a network of twenty community action agencies, one city and one non-profit. This network collectively provides fuel assistance, weatherization and heating repair and replacement under the supervision of the Department of Housing and Community Development which administers these HHS and DOE funded programs for the Federal Government.

SUMMARY OF REQUEST

The network that delivers LIHEAP in Massachusetts offers the interconnected programs noted above, with the goals of providing assistance in paying heating bills, while stretching the available LIHEAP benefits through comprehensive weatherization measures and replacement of inefficient and inoperable heating systems. The mutually-supportive nature of these interconnected programs provides not only bill payment assistance but also necessary health and safety benefits that protect our most vulnerable citizens; young children, elderly, disabled , veterans and those who work hard every day just to provide the basic needs of survival and everyday living for themselves and their families. These programs also work in concert to improve energy conservation and efficiency to ensure the dollars spent on heating benefits are maximized to the fullest extent possible. This combination of LIHEAP and weatherization/energy efficiency funding not only directly benefits those who utilize it, but also increases the cost effectiveness of the LIHEAP funding.

LIHEAP was funded at $3.69 billion last year. Massachusetts legislators, recognizing the necessity to supplement the Federal benefits in a State with cold winters and high energy prices, passed a $30 million supplement to those Federal funds. This provided desperately needed resources to help eligible clients with their energy costs. The recognition of the benefit this program provides underscores the importance of increased funding at the Federal level to meet the need that currently exists. $5.1B was allocated the last time the program was authorized in 2005. LIHEAP has seen its funding dwindle since its high in 2009 as the need continues to increase. For the past 3 years, the current administration has proposed eliminating this program altogether which in and of itself is remarkable in the wake of what that would actually mean to real people. However, Congress, and this Subcommittee in particular, have been strong, bipartisan supporters of LIHEAP and MEDA is grateful to you for those continued efforts. We join countless groups and States throughout the country in requesting an increased level of support in fiscal year 2020 not only to continue these efforts, but to maximize the LIHEAP allocation to the fullest extent possible.

ELIGIBILITY AND NEED

LIHEAP is available in Massachusetts to those households that have incomes up to 60 percent of the estimated State median income. Eligibility to the fuel assistance program also provides access to weatherization services designed to maximize energy efficiency and heating system repair and replacement to ensure households have heating systems that minimize fuel consumption. In Massachusetts, partnerships have been formed with public utility companies to provide enhanced efficiency services, significant energy discounts, protections from termination of service and responsible payment options for those who participate in LIHEAP further enhancing the benefits of this program.

While Massachusetts takes more than 185,000 applications for LIHEAP annually, we recognize that this is only a fraction of individuals and families who should be participating in the program. Efforts to make the program more accessible and well-known are paramount to the outreach efforts all our LIHEAP partners engage in every year. The numbers also clearly show that over the lifetime of this program, funding and participation run hand in hand. Simply put, the more funding provided the more eligible participants who are served.

Every year, the agencies that administer LIHEAP work with clients to address emergency heating situations. The elderly and disabled, who rely on medications in order to survive, will often forgo medical needs in order to heat their homes, making them susceptible to larger health problems. They may not be able to pay their heating costs due to high prescription and medication costs and spend their winters nearly freezing, or worse, actually freezing to death. Families with small children must make similar choices between heating their homes adequately or keeping everyone fed. These are not decisions that should have to be made when we live in a country that has the wealth and prosperity which we currently enjoy. We must protect our veterans, our children, our elderly and those who cannot properly fend for themselves to the best of our ability. This program allows us to do that in a humane and constructive way and provides participants with the dignity to properly support those they love and care for. Desperation leads to bad decisionmaking, a helping hand and a willingness to help leads to hope and a brighter future.

FUNDING REQUEST

The House has requested $3.84 billion in LIHEAP funding for fiscal year 2020 which is a $150 million increase over fiscal year 2019. In the past, LIHEAP funding has been authorized by as much as $5.1B through the Energy Policy Act of 2005, and actually appropriated at that level a decade ago, but has seen subsequent appropriations decrease over the past several years. Again, the current Administration has requested that the program funding be eliminated from the budget completely. However, there has always been strong bipartisan support from both the House and Senate in recognizing the need to make available the important services LIHEAP provides. This support is absolutely essential for those who struggle to maintain basic services where they live during the winter against the many dangers cold and freezing temperatures can have without adequate resources to support a healthy living environment. We therefore urge this Subcommittee to strongly consider not only supporting their House counterparts, but to increase funding to more adequately address the obvious need.

Thank you for the opportunity to express the concerns and support the Massachusetts Energy Directors Association has for these necessary and vital programs and the need for adequate funding to keep them running. On behalf of the twenty-two administering agencies and the hundreds of thousands of people who are assisted by LIHEAP in the Commonwealth as well as the millions of households that rely on these programs nationally, we thank you for your consideration of this request.

[This statement was submitted by Darlene Gallant & Peter Wingate, Co-Chairs, Massachusetts Energy Directors Association.]

PREPARED STATEMENT OF MEALS ON WHEELS AMERICA

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

Thank you for the opportunity to present testimony concerning fiscal year 2020 appropriations for the Older Americans Act (OAA) Nutrition Program, administered by the Administration for Community Living's (ACL) Administration on Aging within the U.S. Department of Health and Human Services (HHS). I am submitting this statement on behalf of Meals on Wheels America, the network of thousands of community-based senior nutrition programs operating throughout the country and the 2.4 million seniors who receive these essential congregate and home-delivered nutrition services.

We are grateful for the ongoing support that the Subcommittee has shown for this program, which improves the health and wellbeing of older adults by preventing and combatting hunger and social isolation. While recent appropriations increases in fiscal year 2018 and fiscal year 2019 have provided a needed investment in our Nation's aging service and support network, the fact remains that current funding levels are still insufficient to keep pace with demand due to a growing senior population, rising costs of inflation and existing unmet need. In fiscal year 2020, we urge you to build on the longstanding bipartisan, bicameral support for the OAA Nutrition Program by funding the program at a total of $1 billion—an increase of $93 million (10 percent) over fiscal year 2019 levels. This is the amount passed by the House Committee on Appropriations last month, and we ask that you provide this same level of funding in the Senate's fiscal year 2020 Labor-HHS-Education Appropriations Bill. Specific line-item requests are:

—Congregate Nutrition Services (Title III C–1)—$525,000,000
—Home-Delivered Nutrition Services (Title III C–2)—$305,000,000
—Nutrition Services Incentives Program (NSIP) (Title III)—$170,000,000

Since 1965, the OAA has been the primary piece of legislation supporting vital services and supports for older adults age 60 and older and their caregivers, with congregate and home-delivered services being the only Federal programs designed to meet both the social and nutritional needs of our Nation's seniors at greatest risk of hunger and isolation. For decades, the OAA Nutrition Program has provided nutritious meals, friendly visits, safety checks and community connections to older adults, consequently improving countless lives and saving considerable taxpayer dollars. This public-private partnership has not only withstood the test of time, but has established itself as a highly effective and trusted program that enables seniors to live longer in their homes, where they want to be.

Despite the OAA Nutrition Program's efficacy and broad support from the public, policymakers and seniors themselves, the community-based nutrition providers that offer OAA services face a myriad of financial challenges. Such constraints have inhibited the program's ability to expand and diminished its reach, despite a period of unprecedented growth in the older adult population.

Greater investments must be made in community-based programs like Meals on Wheels, as they comprehensively address the issues of senior hunger, isolation and loss of independence by delivering so much more than just a meal. If properly funded, the OAA Nutrition Program would reach more of our Nation's most vulnerable and frail seniors—such as the costliest 5 percent of beneficiaries who account for 42 percent of Medicare fee-for-service spending—preventing unnecessary healthcare expenditures like emergency department visits, hospital admissions and readmissions, and premature placement in institutionalized care.

INSUFFICIENT FEDERAL FUNDING THREATENS A GROWING NUMBER OF SENIORS

Nine and a half million seniors (13 percent) face the threat of hunger and approximately 17 million seniors (24 percent) live alone, placing them at greater risk of the harmful health effects of food insecurity, malnutrition and social isolation. Food insecure older adults have worse health outcomes than those who are food secure, with increased risk for heart disease, depression and decline in cognitive function and mobility. Negative health effects associated with social isolation are comparable to those of smoking 15 cigarettes per day. Despite the well-founded understanding of the relationship between healthy aging and access to nutritious food and regular socialization, millions of seniors struggle to meet these basic human needs.

While the OAA Nutrition Program plays a fundamental role in addressing the prevalent issues of senior hunger and isolation, Federal funding for the program has fallen behind with respect to demographic shifts and inflation. Even with appropriations increases in fiscal year 2018 and 2019, total funding for all OAA programs—of which the Nutrition Program makes up the largest share (44 percent)—amounts to an average annual increase of only 1 percent since 2001, and since 2011 has failed to keep pace with the growing age 60+ population. Adjusting for inflation, funding for the OAA Nutrition Program decreased by $80 million (8 percent) between fiscal year 2001 and 2019.

The long-term inadequate funding for the OAA Nutrition Program has caused a wide gap between seniors served and those who need services but are not receiving them. A Government Accountability Office study revealed that 83 percent of low-income, food insecure seniors do not receive the meals that they likely need. And, approximately 21 million fewer meals were served in 2017 than in 2005, while waitlists for seniors seeking meals continue to mount in communities nationwide. In fact, results from a national survey we fielded to our Membership indicate that almost half of senior nutrition programs report a waitlist for meals (for those programs allowed to keep one) and that the overwhelming majority cite lack of funding as the reason. In the absence of significant future appropriations increases, the consequences of funding deficits will undoubtedly worsen, especially as the senior population is projected to reach over 118 million by 2060.

SERVING THOSE WITH THE GREATEST SOCIAL AND ECONOMIC NEED

To address the growing demand for services, the OAA Nutrition Program provided 220 million congregate and home-delivered meals in 2017. The OAA exists to support seniors in the greatest social and economic need, and as such, effectively targets these nutrition services with limited financial resources. For many seniors participating in the program, staff members and peers at a congregate dining facility, or a volunteer delivering Meals on Wheels, may be the only individual(s) she or he sees that day; and the meal received often accounts for the majority of her or his food intake for the day.

The profile of clients receiving home-delivered meal services reveals a high degree of vulnerability:

—79 percent are age 75 and older
—69 percent are women
—35 percent live at or below poverty level
—59 percent live alone
—25 percent live in rural areas
—15 percent are veterans
—28 percent are a racial and/or ethnic minority
—82 percent take 3 or more medications daily

Additionally, about 74 percent of congregate nutrition program clients and 80 percent of home-delivered meal clients have at least one chronic condition. The vital services financed by the OAA Nutrition Program allow seniors with these risk factors to remain safer, healthier and less isolated in their own homes and communities.

THE SOLUTION EXISTS

With public spending on healthcare rising steeply each year—attributable in part to a rapidly growing senior population with complex health needs—it is imperative that we invest in cost-effective programs that promote health and reduce healthcare utilization.

The results of a 2015 study commissioned by Meals on Wheels America found that seniors on waitlists for nutrition services who received a 15-week intervention of daily home-delivered meals were more likely to report improvements in mental health, self-rated health and feelings of isolation and loneliness, as well as reduced rates of falls and decreased concerns about their ability to remain in their home, when compared to baseline. In a more recent study, home-delivered meal participants from a sample of older adults dually-eligible for Medicare and Medicaid were observed to experience fewer emergency department visits and lower healthcare spending than the non-participant controls, suggesting the program's potential to reduce healthcare costs among the most vulnerable patients.

The majority of seniors receiving OAA nutrition services experience positive results. Home-delivered meal clients, in particular, self-report improved nutritional intake, health and independence due to their participation, saying that the meals help them:

—Eat healthier food (79 percent)
—Improve health (82 percent)
—Stay in their own home (92 percent)
—Feel better (89 percent)

Fortunately, the infrastructure and cost-effective interventions to support this unique population by promoting and maintaining their health and independence already exist through the OAA network of more than 5,000 local, community-based programs, which has the capacity to serve significantly more seniors, if provided more funding to do so.

DELIVERING A STRONG RETURN ON INVESTMENT FOR OUR NATION

We understand the challenging decisions you are responsible for making in the coming months with respect to the Federal budget; however, we are asking for a $93 million increase for the OAA Nutrition Program because of the strong return it delivers to seniors and taxpayers alike. While spending on Medicare and Medicaid continues to rise, a senior can receive Meals on Wheels for a whole year for approximately the same cost or less as one day in the hospital or ten days in a nursing home, allowing her or him to remain in their home with comfort and dignity and helping to drive down preventable healthcare expenditures. As such, we also urge the Senate to adopt a bipartisan budget agreement that would raise the overall spending limits so that critical non-defense discretionary programs, such as congregate and home-delivered meals, do not face the devastating threat of sequestration.

As the Subcommittee develops a Labor-HHS-Education Appropriations Bill for fiscal year 2020, we ask that you provide, at a minimum, $1 billion for the OAA Nutrition Program. As additional evidence of support for this increase, 39 Senators signed onto a bipartisan Dear Colleague letter on April 12, 2019 calling for an overall 12 percent increase above fiscal year 2019 levels to all OAA programs. Again, we thank you for your leadership, continued support and consideration and are pleased to offer our assistance and expertise at any time throughout the appropriations process.

[This statement was submitted by Ellie Hollander, President and CEO, Meals on Wheels America.]

PREPARED STATEMENT OF THE MEDICAL LIBRARY ASSOCIATION AND ASSOCIATION OF ACADEMIC HEALTH SCIENCES LIBRARIES

I, Mary M. Langman, Director, Information Issues and Policy, Medical Library Association (MLA), submit this statement on behalf of MLA and the Association of Academic Health Sciences Libraries (AAHSL). MLA is a global, nonprofit, educational organization with a membership of more than 400 institutions and 3,000 professionals in the health information field. AAHSL supports academic health sciences libraries and directors in advancing the patient care, research, education and community service missions of academic health centers through visionary executive leadership and expertise in health information, scholarly communication, and knowledge management.

We thank the Subcommittee for the opportunity to submit testimony supporting appropriations for the National Library of Medicine (NLM), an agency of the National Institutes of Health (NIH), and recommend $463,599,000 for NLM in fiscal year 2020, the funding level provided by the Committee on Appropriations in House Report 116–62.

Working in partnership with the NIH and other Federal agencies, NLM is the key link in the chain that translates biomedical research into practice, making the data and results of research readily available to all who need it. NLM is also a leader in data science and open science and is facilitating implementation of NIH-wide efforts data science activities. As health sciences librarians who use NLM's programs and services every day, we can attest that NLM resources literally save lives, making NLM an investment in good health.

NLM Amplifies NIH Investments in Biomedical Research

NLM maximizes the return on investment in research conducted by the NIH and other organizations. It makes the results of biomedical information accessible to researchers, clinicians, business innovators, and the public, enabling such data and information to be used more efficiently and effectively to drive innovation and improve health. NLM's budget supports intramural services, research, and programs that sustain the Nation's biomedical research enterprise and more-it builds, sustains, and augments a suite of almost 300 databases which provide information access to health professionals, researchers, educators, and the public. It also supports the acquisition, organization, preservation, and dissemination of the world's biomedical literature and information. To support exponential growth of data and information, in fiscal year 2020 and beyond, NLM's budget must continue to be augmented to support expansion of its information resources, services, research, and programs which collect, organize, and develop new ways to make the rapidly expanding biomedical knowledge resources and data readily accessible.

NLM plays a critical role in NIH's open science and data science initiatives and in enhancing interoperability of health information technology, including electronic health records (EHRs). NLM leads the development, maintenance and dissemination of key standards for health data interchange that are now required of certified EHRs. NLM also addresses Congressional priorities through ClinicalTrials.gov, response to the opioid crisis, and disaster preparedness and response efforts.

Growing Demand for NLM's Information Services

NLM delivers more than 50 trillion bytes of data to millions of users daily, which helps researchers advance scientific discovery and accelerate its translation into new therapies; provides health practitioners with information that improves medical care and lowers its costs; and gives the public access to resources and tools that promote wellness and disease prevention. Every day, medical librarians across the Nation use NLM's services to assist clinicians, students, researchers, and the public in accessing information to save lives and improve health. Without NLM, our Nation's medical libraries would be unable to provide quality information services that our Nation's health professionals, educators, researchers, and patients increasingly need.

NLM's data repositories and online integrated services such as GenBank, dbGaP, Genetics Home Reference (GHR), PubMed, and PubMed Central (PMC) are revolutionizing medicine and ushering in an era of personalized medicine. GenBank is the definitive source of gene sequence information. Some 2 million users accessed consumer-level information about genetics from GHR which contains more than 2,500 summaries of genetic conditions, genes, gene families, and chromosomes. PubMed, with 29 million references to the biomedical literature, is the world's most heavily used source of bibliographic information with more than 1.3 million new citations added in fiscal year 2018 and more than 2.9 million users each day. PubMed Central (PMC) is NLM's digital archive, which provides free public access to the full-text versions of more than 5.1 million biomedical journal articles, including those produced by NIH-funded researchers and also public assess to research funded by ten other Federal agencies. On a typical weekday approximately 2.5 million users download more than 5 million articles from PMC.

NLM's traditional print and electronic collections increase steadily each year, standing at more than 21 million items-books, journals, technical reports, manuscripts, microfilms, photographs and images. NLM ensures the availability of this information for future generations, making it accessible to all Americans, irrespective of geography or ability to pay, and enabling citizens to make the best, most informed decisions about their healthcare.

NLM's MedlinePlus provides consumers with trusted, reliable health information on 1,000 topics in English and Spanish. It attracts more than 277 million visitors annually. NLM continues to enhance MedlinePlus and disseminate authoritative information via the website, a web service, and social media. MedlinePlus and MedlinePlus en Español have been optimized for easier use on mobile phones and tablets. NIH MedlinePlus Magazine and NIH MedlinePlus Salud are available in doctors' offices nationwide, and NLM's MedlinePlus Connect enables clinical care organizations to link from their EHR systems to relevant patient education materials.

Encourage NLM Partnerships

NLM's outreach programs are essential to the MLA and AAHSL membership and to the profession. Through the National Network of Libraries of Medicine (NNLM), with over 7,100 members nationwide, NLM educates medical librarians, health professionals, and the general public about its services and provides training in their effective use. The NNLM serves the public by promoting educational outreach for public libraries, secondary schools, senior centers and other consumer settings, and its outreach to underserved populations helps reduce health disparities. NLM's "Partners in Information Access" provides local public health officials with online information that protects public health.

Since 2018, the NNLM has partnered with the NIH All of Us Research Program to support community engagement efforts by United States public libraries and to raise awareness about the program. To date, more than 247 libraries across the United States have joined the NNLM All of Us Community Engagement Network to support health literacy by offering free health and wellness resources and programs in local communities.

Data Science and Open Science

NLM is a leader in data science and open science, including the acquisition and analysis of data for discovery and the training of biomedical data scientists. The library aims to strengthen its position as a center of excellence for health data analytics and discovery, and to spearhead the application of advanced data science tools to biological, clinical, and health data. The library aims to fund research that proposes state of the art methods and approaches to address problems and ethical issues with large health data sets, tools used to analyze them (e.g. artificial intelligence (AI)), or inferences drawn based on them. For example, exploring approaches to characterize the data, correct biases or compensate for missing data, and analyze health data while preserving confidentiality, accuracy, and security. NLM is building a workforce for data-driven research and health by funding PhD-level research training in biomedical informatics and data science. The library also partners across the NIH to promote and facilitate inclusion of data science and open science core skills in NIH training programs, and is expanding training for librarians, information science professionals, and other research facilitators. NLM is fostering a culture that advances science and ensures the development and retention of a diverse, safe, and respectful workforce for data-driven research and health well into the future.

Emergency Preparedness and Response

NLM's Disaster Information Management Research Center collects and organizes disaster-related health information, ensures effective use of libraries and librarians in disaster planning and response, and develops information services to assist responders. NLM responds to specific disasters worldwide with specialized information resources appropriate to the need, including opioid response, bioterrorism, chemical emergencies, fires and wildfires, earthquakes, tornadoes, and pandemic or epidemic disease outbreaks (e.g., Zika, HIV/AIDS). MLA and NLM's Disaster Information Specialization builds the capacity of librarians to provide disaster-related health information outreach. Working with libraries and publishers, NLM provides free full-text articles from hundreds of biomedical journals and reference books to medical teams responding to disasters.

NLM Conducts and Invests in Biomedical Informatics Research and Health Information Technology

NLM conducts and invests in informatics research, training, and the application of advanced computing and informatics to biomedical research and healthcare delivery. Through its Intramural Research Program, NLM's National Center for Biotechnology Information (NCBI) focuses on computational biology, genomics, and biological data banks, and the Lister Hill National Center for Biomedical Communications (LHC) is a leader in clinical information analytics and standards.. A leader in supporting the development, maintenance, and free, nationwide dissemination of standard clinical terminologies, NLM partners with the Office of the National Coordinator for Health Information Technology to support adoption of interoperable EHRs that enable health information exchange. NLM also develops tools to make it easier for EHR developers and users to implement accepted health data standards and link to relevant patient education materials. NLM grant support contributes to research and development of electronic health records (EHR) systems and personal health libraries. NLM is expanding its extramural grant programs to support growing demand for innovation in data science, including methods for extracting meaning from data, such as genomic sequences or clinical data from EHRs. Many of today's biomedical informatics leaders are graduates of NLM-funded informatics research training programs at universities nationwide. NLM also funded five new Small Business Innovation Research and Technology Transfer awards to facilitate innovations, such as block-chain enabled decision support to safeguard privacy and security of patients and research participants.

Dissemination of Clinical Trial Information

ClinicalTrials.gov, the world's largest clinical trials registry, now includes more than 287,000 registered studies and summary results for more than 33,000 trials. As health sciences librarians who fulfill requests for information from clinicians, scientists, and patients, we applaud NIH and NLM for implementing requirements for clinical trials registration and results submission consistent with the FDA Amendments Act of 2007, and for applying them to all NIH-supported clinical trials. These efforts increase transparency of clinical trial results and provide patients and clinicians with information to guide healthcare decisions. They also ensure biomedical researchers have access to results that can inform future protocols and discoveries.

Improving Public Access to Funded Research Results

The Department of Health and Human Services (DHHS) announced a common policy approach to expand public access to the results of HHS-funded scientific research. Its operating divisions, and other Federal agencies, will use NLM's PubMed Central (PMC) as a common repository to provide free public access to peer-reviewed publications resulting from research funded by NIH and ten other Federal agencies.

We look forward to continuing this dialogue and thank you for your efforts to support funding of at least $463,599,000 for NLM in fiscal year 2020, with additional increases in future years.

PREPARED STATEMENT OF THE MENDING MINDS FOUNDATION

Mr. Chairman,

It is an honor to provide testimony to the Subcommittee on behalf of the Mending Minds Foundation. I am here on behalf of the thousands of children across the country who have had their lives turned upside down by Childhood Post-Infectious Neuroimmune Disorders—CPIND. In CPIND, following infection, it is believed that antibodies that would normally fight infection "go rogue" and attack the brain. This results in an inflammatory process that can lead parents like me to watch helplessly as our children experience debilitating neurological and behavior changes.

We are asking that you include language in the Committee's report encouraging the National Institutes of Health (NIH) to prioritize research efforts on Childhood Post-Infectious Neuroimmune Disorders (CPIND). We are also asking that the increased efforts made by NIH be reported back to the Committee, including findings on incidence, causes, diagnostic criteria, and treatment of these conditions. We are asking, too, that the report language encourages NIH to find ways of further understanding conditions related to CPIND to improve patient's clinical care.

All three of my children have been diagnosed with a neuroimmune disorder called PANDAS, which stands for Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections. A similar condition termed PANS, Pediatric Acute-onset Neuropsychiatric Syndrome, is experienced by many other children.

Both are devastating.

Children often experience escalating symptoms that appear psychiatric while their underlying infection remains untreated—and parents witness such a significant change happening that their child is almost unrecognizable

Action needs to be taken by NIH to research the causes and treatments of these conditions: that's why I am here today asking for your help.

THE IMPACT OF CPIND

I co-founded Mending Minds with parents, scientists and doctors, to drive serious research to find better treatments to help children with CPIND.

Families of children with CPIND are blindsided. Previously happy childhoods are upended as a child's personality and behaviors completely change, suddenly leaving them with dramatic, debilitating anxiety, obsessive thinking and compulsive behaviors. Some children are unable to separate from parents. Some are unable to attend school, or even leave the house.

When children are able to continue at school, they can experience significant academic declines. Previously successful students suddenly need special education supports, and motor function may decline as well. Often, handwriting skills rapidly decline to the point where some children can no longer write legibly or even at times hold a pencil.

Other "physical" symptoms can also occur-previously potty-trained children suddenly need to wear diapers. Children pull out every hair on their head, a condition called trichotillomania or obsessive hair pulling.

Children as young as four or five suddenly appear anorexic, restricting their eating to just a few food items leading to near starvation because of worries about contaminated food or fear of choking. In extreme cases, some children have to be placed on feeding tubes.

Children experience massive mood swings, fly into aggressive rages, full of irrational explosive anger. Even seven or 8-year-old children can become suicidal, with an obsessive feeling that they have to die. Several children have ended their lives, and many others have been removed from their families and hospitalized for psychiatric conditions.

Our family's journey is typical. After years of worsening behaviors and symptoms, with misdiagnoses along the way, we finally arrived at the true cause of our children's illness: an undiagnosed, untreated strep infection—the same bacteria that causes a sore throat—that set off symptoms that appeared psychiatric in nature.

What is believed to happen in CPIND is that following an infection, in possibly genetically susceptible children, antibodies and/or immune cells that would normally fight infection "go rogue" and attack the brain. The resulting inflammatory process can lead to debilitating neurological and behavioral changes.

CONNECTION BETWEEN MENTAL HEALTH AND INFECTION

PANDAS and PANS are part of a group of poorly understood and only recently defined medical conditions that arise after infection. PANDAS was first defined in the late 1990s by Dr. Susan Swedo at the National Institute of Mental Health. Dr. Swedo described PANDAS as "a subset of children and adolescents who have obsessive compulsive disorder (OCD) and/or tic disorders, and in whom symptoms worsen following infections such as 'Strep Throat' and Scarlet Fever."

PANDAS is believed to be a variation of rheumatic fever. Rheumatic fever can develop if strep throat infections are not treated properly in a timely fashion, setting off an immune response where antibodies attack the heart, kidneys, joints, or brain.

PANS was defined in 2010 and, according to the NIH, "includes all cases of acute-onset OCD, not just those associated with streptococcal infections."

Given the significant burden that these diagnoses place on families and the medical system, you may be wondering why these conditions are still relatively unknown. To be clear, the symptoms that these children are exhibiting—such as severe anxiety, obsessive compulsive symptoms, and motor and vocal tics—are not in debate.

What remains under-researched is the idea that these symptoms are initiated by a common infection—in this case "strep throat."

However, a recently published study of over one million children in Denmark suggests that children have eight times the risk of developing OCD following an infection. Additionally, a growing body of research exists connecting infection to mental health changes in conditions like schizophrenia.

Studies like these raise big questions about mental illness—which can mean a lifetime of psychiatric mediations—and how this might change if underlying biological causes like infection were better understood. With over 30 percent of adolescents currently meeting criteria for an anxiety disorder, the need for more resources to understand these phenomena is clear.

There is a significant lack of NIH funding to support research into these disorders and to address the issues of awareness, diagnosis and treatment.

THE COST OF CPIND

Recognizing the true cost and prevalence of these disorders is imperative. There is no "biomarker" or easy way to diagnose these conditions. Because there is limited awareness or clinical understanding, children, like ours, are frequently diagnosed with purely psychiatric conditions while their underlying infections go untreated.

This results in a devastating escalation of symptoms, which places tremendous burden on caregivers and educational and healthcare systems. Families like ours spend tens of thousands of dollars and travel far and wide for treatment—specialists are hard to find and waitlists for medical care can be as long as 2 years. School systems face a huge burden of putting special education supports into place for children who need increased academic and behavioral support.

As symptoms progress, more invasive treatments are often sought by parents, which are often not covered by insurance and sometimes in-patient hospitalization is needed. A recent survey by Massachusetts General Hospital suggests that as many as one-third of children diagnosed with PANDAS have gone to the emergency room in the course of their medical care.

ASKING FOR YOUR SUPPORT

I want my family's experience with a devastating post-infectious neuroimmune condition to help thousands of other children who are suffering. With your support, more can be done to help better understand and treat these awful disorders and help children across the United States regain their childhoods.

Parents and the Mending Minds Foundation are doing all we can to support our children—won't you please join with us to help solve this Nation-wide health problem?

Thank you for your consideration.

[This statement was submitted Amanda Peel Crowley, Founding Member, Mending Minds Foundation.]

PREPARED STATEMENT OF THE MESOTHELIOMA APPLIED RESEARCH FOUNDATION

Dear Chairman Blunt and Ranking Member Murray:

We respectfully request your support to include $400,000 in the fiscal year 2020 Labor, HHS, Education and Related Agencies Appropriations bill for funding through the National Institute for Occupational Safety and Health (NIOSH) within the Centers for Disease Control and Prevention (CDC) to develop a National Mesothelioma Patient Registry.

Mesothelioma is a form of cancer that affects the smooth lining of the chest, lungs, heart, and abdomen. The thin layer of tissue surrounding these organs is made up of mesothelial cells, hence the name mesothelioma. As the cancer progresses, the lining thickens, progressively invading and impairing the function of the organs it surrounds. This disease has devastating symptoms such as chest pain, difficulty breathing and bodily weakness and is among the deadliest cancers, as patients typically survive approximately 1 year from the time of diagnosis.

Mesothelioma is known to be caused by exposure to asbestos. The CDC reports that despite regulatory actions to decrease the use of asbestos, the annual number of mesothelioma patients has increased by nearly 5 percent from 1999 to 2015. There is an established history of asbestos exposure in the U.S. military, and approximately one third of mesothelioma cases have been shown to involve exposures to Navy personnel or civilian workers in Naval shipyards.

NIOSH, a part of the CDC, has started the initial steps to create a national mesothelioma patient registry that will establish priorities for successful outcomes, develop and revise standards of care and treatment best practices for patients, share evidence-based information between physicians across the country, implement benchmarks to improve care, and identify centers that provide the most beneficial care to patients. The information collected in the patient registry will be necessary for researchers to develop additional treatments and a cure for this disease.

Sincerely.

[This statement was submitted by Mary Hesdorffer, Executive Director, Mesothelioma Applied Research Foundation.]

PREPARED STATEMENT OF METAVIVOR

FISCAL YEAR 2020 APPROPRIATIONS RECOMMENDATIONS

—Please provide the National Institutes of Health (NIH) with an increase of at least a $2.5 billion for fiscal year 2020 to bring total agency funding up to a minimum of $31.6 billion annually.

—Please continue to support additional investment for the cancer “moonshot” as outlined by the 21st Century Cures Act and otherwise ensure the National Cancer Institute (NCI) has adequate resources.

—Please continue to emphasize the importance of Federal research activities focused on controlling and eliminating cancer that has already disseminated through committee recommendations and timely oversight of ongoing activities.

—Please support emerging efforts to modernize the Surveillance, Epidemiology, and End Results (SEER) Registry Program to better capture the experience of patients impacted by stage IV metastatic breast cancer.

Chairman Blunt, Ranking Member Murray, and distinguished members of the Subcommittee, thank you once again for considering the views of METAvivor and the stage IV metastatic cancer community as you work on fiscal year 2020 appropriations for medical research. The community is deeply grateful for the $2 billion funding increase provided to NIH in fiscal year 2019. Please maintain this commitment to supporting innovative medical research moving forward.

ABOUT METAVIVOR

What is my involvement? I am President of METAvivor, a patient-founded, volunteer-led, grassroots organization that funds vital research to increase longevity and quality of life for metastatic cancer patients. It is our sincerest hope that one day efforts such as ours, efforts we hope you will also support, promote and undertake, will one day make a difference for the more than 500,000 patients who die annually of a metastasized cancer in the U.S. alone. Our disease is defined by the spread of cancer from its original location to other vital organs in the body, such as the bones, lungs, liver or brain. At present it is almost always fatal. METAvivor was founded in 2009 by four terminally ill, metastatic cancer patients because as everyone around them was dying, they saw that no one was dedicated to, or showed any interest in, funding the research that could make a difference for their community. Thus METAvivor was founded for the sole purpose of funding such research. Within 12 months two of the founders had died. But they pressed ahead. A third died. More joined. To date they have awarded $4.2 million in research grants despite sustaining the deaths of 10 Board members. The organization continues to grow, but there are limits to what we can achieve alone. We need more funding for stage IV metastatic cancer. Far more funding is needed; far more interest is needed; and far more research must be accomplished. After 9 years of going this alone it is high time other organizations; especially the NCI which has a national responsibility for all American citizens; even the terminally ill, does right by our greater community and adds to its portfolio a program of respectable size that addresses the issue and funds the research that will ultimately, significantly extend life with quality and hopefully end death for at least a segment of our community.

THE FACTS ABOUT METASTATIC STAGE IV CANCER

Roughly 600,000 Americans die annually from cancer. Ninety percent of these deaths are caused by a metastasis. If we wish to lower the death rate, we must tackle metastasis. For more than 20 years, the primary focus has been on preventing cancer altogether and if that fails, catching it early. But aside from convincing people to stop smoking, forbidding smoke in common areas and removing colon polyps prior to malignancy, little progress has been made. For most cancers, it is believed there are multiple causes, few if any of which are known, making prevention a formidable and more likely unachievable goal. Improved equipment has allowed some cancers to be diagnosed as early as stage 0; however, stage 0 patients are also metastasizing. And although we are slowly adding drugs to the treatment repertoire, a treatment's effectiveness often runs out in 2–3 months. Thus, we empty our toolbox of drugs far too quickly and we, metastatic patients, die.

Sustained focus is needed on research efforts intended to help control and eliminate cancer that has already disseminated.

MY STORY

My name is Beth Fairchild. In my former life, I was an artist, a mother, a wife, a daughter, a friend. Now, while I may still be all of these, I have added fearless fighter and breast cancer advocate to the list of things that make me, me. This is my new, cancer life. At 34, my life was pretty normal. My husband and I were successful business owners. We were raising our daughter and preparing to adopt another. I was happy in my personal life and career, I worked out daily and ate healthy. Then, there it was: cancer. After months of complaining of intestinal discomfort and lack of energy, my doctors discovered my ovaries were the size of grapefruits and in danger of rupture. They had to come out and, because I had a family history (my mom was diagnosed with breast cancer at 44 and my paternal grandmother was dead and buried at 33), I decided on a total hysterectomy. My surgery was the day after Mother's Day. Tissue samples were sent off to pathology, and two days later, I was told I had breast cancer. After my diagnosis, I came home to die. I was in agony from the pain of surgery and my head was spinning. I couldn't see past that moment in time. But it got better. Every. Day. My body healed. I got stronger. I endured 18 weeks of chemo and survived! I was a 34-year-old, post-menopausal, bald-headed, terminal cancer patient, but I was alive and LIVING. I set out to take back control of my life.

My children were my first motivation. I saw the fear in their eyes. Mommy couldn't assure them that things would be ok, but I could show them I wasn't going to give up. I talked candidly with them about my condition and treatment. I got up every morning and took them to school, even the days I didn't feel like it. I was a mom first, and they kept me going. My job kept me going. I'm an artist. I make tattoos. My husband and I have five studios and I have made my career in the tattoo industry. My specialty is permanent cosmetics and areola restoration for breast cancer patients. Ironic, huh? On the days I had to see my breast cancer clients, I knew what the procedure meant to them, so I would leave chemo and go straight to the studio and help a woman feel whole again. It was therapy to me. Then, I found support groups. I had wanted to talk to and be with other women like me.

There were several groups available in my town in North Carolina; however, I was the youngest person there by at least 20 or 30 years. I'm in no way minimizing the severity of cancer in older patients, but it was hard to hear others speak about not seeing their grandkids grow into adults when I felt like I wouldn't even see my daughter graduate from high school. When I was diagnosed with stage IV breast cancer, I was in the prime of my life. Cancer is a daily struggle in any season of life, but the under-40 demographic has to not only juggle surgeries and treatments, but oftentimes careers, new marriages, or maybe dating. Many have young kids already, but some women will never experience childbirth because their ovaries are suppressed from hormonal treatments or, like me, have had them removed in order to slow the cancer's progress. Realizing the sacrifices of these men and women, as well as myself, made, the lack of awareness about metastatic cancer was disturbing. I thought my condition was rare, but, turns out, not so much. There are 600,000 people with metastatic cancer. There are 41,000 with metastatic breast cancer that die every year, which is about 113 per day. We must increase research funding for new treatments. We must make sure that families like mine have hope and that my two little girls know that we are working toward life extending treatments.

Through local events and social media, I have tried to help spread the under-reported message of metastatic breast cancer. I started a social media movement on Facebook called Stomp Out BC using the hashtag #dontignorestageiv created by METAvivor. I am now the president of METAvivor and work alongside other to raise funds for and draw attention to metastatic breast cancer until my dying breath. No one can say for sure when my time will be up, or even for certain that this "thief of life" we call cancer will be the cause, but short of a miracle-and I do still believe in miracles-I will die with this cancer in my body. In the interim, I hope the lives of the more than 600,000 people with stage IV metastatic cancer is considered when making decisions about the future of cancer research and especially funding the Cancer Moonshot Initiative. METAvivor has worked hard to fund research. Since 2009, we have funded $2.4 million but we need more...stage IV metastatic cancer needs more research.

SEER REGISTRY

A timely opportunity to advance metastatic cancer research involves modernizing the Surveillance, Epidemiology, and End-Results Registry (SEER) so that it more accurately captures patient data. The House included the recommendations below in the Committee Report accompanying its LHHS Bill and we hope the Senate will similarly support this language to move this timely effort forward.

Surveillance, Epidemiology, and End Results [SEER] Registry.-The Committee notes recent discussions about modernizing the SEER Registry and filling in key data gaps, such as metastatic recurrence for stage IV metastatic breast cancer. NCI is encouraged to advance this effort in a systematic and meaningful way that ultimately improves SEER Registry infrastructure and capabilities.

Thank you for your time and your consideration of these requests.

[This statement was submitted by Beth Fairchild, President, METAvivor.]

PREPARED STATEMENT OF THE MINE SAFETY AND HEALTH ADMINISTRATION

We are writing in regard to the fiscal year 2020 Budget Request for the Mine Safety and Health Administration (MSHA), which is part of the U.S. Department of Labor. In particular, we urge the Subcommittee to support a full appropriation for State assistance grants for safety and health training of our Nation's miners pursuant to section 503(a) of the Mine Safety and Health Act of 1977. MSHA's budget includes an amount of not less than $10,537,000 for State assistance grants. We urge the Subcommittee to fund these grants at this statutorily authorized level for State assistance grants so States are able to meet the training needs of miners and to fully and effectively carry out State responsibilities under section 503(a) of the Act. We further urge the Subcommittee to not adopt the proviso the Department of Labor has attached to its proposal for funding State assistance grants. We believe the States can more than justify the need for funding at the statutorily authorized level.

The Interstate Mining Compact Commission is a multi-State governmental organization that represents the natural resource, environmental protection and mine safety and health interests of its 26 member States. The States are represented by their Governors who serve as Commissioners.

A troubling aspect of the portion of MSHA's proposed budget dealing with State assistance grants is the proviso attached to it, which grants the following authority to the Secretary of Labor:

> [A]mounts available for State assistance grants may be used for the purchase and maintenance of new equipment required by the final rule entitled "Lowering Miners Exposure to Respirable Coal Mine Dust, Including Continuous Personal Dust Monitors" published by the Department of Labor in the Federal Register on May 1, 2014 (70 Fed. Reg. 24813 et seq.), for operators that demonstrate financial need as determined by the Secretary[.]

Budget Appendix, p. 755.

We support full funding of $10,537,000 for the State assistance grants that enable the States to provide essential safety and health training for the Nation's coal miners, undiminished by use of these funds for other purposes. The proposed budget goes beyond simply allowing the funding of these State programs to be diminished. It has no limits on the amount of State assistance funds that could be diverted from their intended purpose and used elsewhere under this proviso. Conceivably, the proviso would allow these grants to be eliminated. As written, the budget would allow all of the State assistance grant money to be diverted away from the States. State mine safety and health training programs are important and should fully funded. The money these programs need should not be reduced in order to provide a subsidy for mine operators' compliance with MSHA's respirable dust rule. We urge the Subcommittee to remove this proviso and not include it in any budget bill it produces for the Department of Labor. Section 503 of the Act was structured to be much broader in scope and to stand as a separate and distinct part of the overall mine safety and health program. In the Conference Report that accompanied passage of the Federal Coal Mining Health and Safety Act of 1969, the conference committee noted that both the House and Senate bills provided for "Federal assistance to coal-producing States in developing and enforcing effective health and safety laws and regulations applicable to mines in the States and to promote Federal-State coordination and cooperation in improving health and safety conditions in the Nation's coal mines." (H. Conf. Report 91–761). The 1977 Amendments to the Mine Safety and Health Act expanded these assistance grants to both coal and metal/non-metal mines and increased the authorization for annual appropriations to $10 million. The training of miners was only one part of the obligation envisioned by Congress.

With respect to the training component of our mine safety programs, IMCC's member States are concerned that without full, stable funding of the State Grants Program, the federally required training for miners employed throughout the U.S. will suffer. Our experience over the past 35 years has demonstrated that the States are often in the best position to design and offer mine safety and health training in a way that insures that the goals and objectives of Sections 502 and 503 of the Mine Safety and Health Act are adequately met. We greatly appreciate Congress' recognition of this fact and this Subcommittee's strong support for State assistance grants, especially in past years when the Administration sought to eliminate or substantially reduce those moneys.

Thank you for the opportunity to present our views on the proposed fiscal year 2020 budget for MSHA and the Department of Labor.

[This statement was submitted by Thomas L. Clarke, Executive Director, Interstate Mining Compact Commission.]

Prepared Statement of Howard and Gail Morris

OVERVIEW

We are the Pennsylvania and Florida grandparents of a 6 year old boy in Pennsylvania who was diagnosed in 2018 with Celiac Disease, a serious autoimmune disease that afflicts about 3 million Americans. We echo the recent testimony of Marilyn Geller, CEO of the Celiac Disease Foundation, to the U.S. House of Representatives Committee on Appropriations, Subcommittee on Labor, Health and Human Services, Education, and Related Agencies, when Geller stated, "If I leave you with one message today, it is that Celiac Disease is, in fact, a serious autoimmune disease that is not being taken seriously enough by our government."[1]

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[1] Testimony of Marilyn G. Geller, CEO, Celiac Disease Foundation (Los Angeles, CA), to the U.S. House of Representatives Committee on Appropriations, Subcommittee on Labor, Health

Continued

Today, many people have conflated the popular Gluten Free diet craze with the medically required Gluten Free diet for people with Celiac Disease. In 1952, it was first discovered that Gluten was the trigger of Celiac Disease. To cure Celiac Disease, we need to fundamentally shift how our government leaders are educated on this disease. Why? Because the current research paradigm for Celiac Disease, one that has existed for many decades, has not delivered a cure or even a way to treat accidental ingestion of Gluten. There is no medicine or surgery available to treat Celiac Disease. To date, Celiac Disease research has produced only a single approved treatment—strict adherence to a lifelong Gluten Free diet with no exceptions! However, as Celiac Disease researchers have found, "[t]here is no such thing as a gluten-free diet because of the constant risk of cross-contact with gluten, and gluten is in 80 percent of our foodstuffs." [2] Additionally, for up to 30 percent of patients, diet alone is inadequate for remission in that it alleviates some symptoms, but does not heal and resolve intestinal damage caused by Celiac Disease.[3]

Anecdotally, we can attest to the treatment burden including the constant concern over cross contamination and inclusion of our grandson in life's numerous daily activities that involve food at home, at school (in Kindergarten) and away from home. Research has shown that the treatment burden of Celiac Disease is comparable to end-stage renal disease, and the partner (or parent) burden is comparable to caring for a patient with cancer.[4]

While the NIH purportedly makes decisions on what diseases deserve Federal research funding based on disease burden and prevalence, NIH has seriously underfunded Celiac Disease over the last decade, even as the number of Americans diagnosed with Celiac Disease has kept increasing. Moreover, as detailed herein, NIH funding for Celiac Disease has significantly trailed comparable diseases that have the same or less prevalence, the same or less disease burden measurements, as well as more than one available treatment option. That is unacceptable! We need the U.S. government, including the NIH and CDC, to step up and invest meaningful resources to find a cure to this debilitating disease that directly impacts the lives of 1 percent of Americans, in addition to their families and/or partners, on a daily basis. Celiac Disease is so serious that it is a "disqualifying condition" from service in the U.S. Military.[5] Many years ago, I (Howard Morris) worked at the NIH and understands the important work that goes on there and the brilliant minds who look at solutions out of the box.

SUGGESTED REPORT LANGUAGE TO THE NIH

We are respectfully asking that the Senate Appropriations Committee include the following Report Language to the National Institutes of Health:

"The Committee recognizes the serious issue of Celiac Disease which affects more than 3 million Americans, and that the number afflicted is growing. To that end, the Committee urges NIH to devote sufficient, focused research to the study of Celiac Disease. To date, NIH has examined symptoms of Celiac Disease and has not focused upon the autoimmune causation underpinning the affliction. Today, the only known treatment for this disease is a Gluten Free diet; but, recent private sector research has revealed that such a treatment is insufficient for many who suffer from Celiac Disease. Therefore, the Committee directs the Office of the Director to dedicate sufficient resources and robust investment toward multi-institute research to better coordinate existing research and focus new research efforts toward understanding causation and ultimately, finding a cure. The Office of the Director is directed to submit its plan for coordination and execution of this research to the Senate Appropriations Committee, including the funding and FTE associated with implementation of this plan, no later than 60 days after the date of enactment of this Act."

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and Human Services, Education, and Related Agencies, April 9, 2019, https://celiac.org/april-2019-congressional-testimony-by-ceo-marilyn-g-geller/?

[2] Ibid, Testimony of Marilyn G. Geller, April 9, 2019.

[3] Celiac Disease Foundation, https://celiac.org/about-celiac-disease/poorly-responsive-celiac-disease/.

[4] "Patient Perception of Treatment Burden is High in Celiac Disease Compared to Other Common Conditions," PMC, National Library of Medicine, National Institutes of Health, July 1, 2014, https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4159418/.

[5] U.S. Department of Defense, "DoD Instruction 6130.03, Medical Standards for Appointment, Enlistment, or Induction into the Military Services," Section 5.12.c.(3), May 6, 2018, https://www.esd.whs.mil/DD/.

What is Celiac Disease?

Answer. An Invisible Illness with a Major Impact on People's Health

According to the University of Chicago, "Celiac disease is an inherited autoimmune disorder that affects the digestive process of the small intestine. When a person who has celiac disease consumes gluten, a protein found in wheat, rye and barley, the individual's immune system responds by attacking the small intestine and inhibiting the absorption of important nutrients into the body."[6] "Specifically, the tiny fingerlike protrusions called villi on the lining of the small intestine are lost [damaged]."[7] 30–40 percent of Americans carry the genes for Celiac Disease, but only about 1 percent have Celiac Disease. No one knows what causes Celiac Disease to activate in some people, but not others. This is one of the key research areas that needs funding. Additionally, Celiac research has the potential to enhance understanding and improve therapies for other auto-immune conditions and unlock the mysteries of the microbiome which may enable treatment for a wide spectrum of diseases.

OUR GRANDSON'S POTENTIAL REACTIONS TO INGESTION OF GLUTEN

For all Celiac Disease sufferers such as our grandson, the Gluten protein (even in trace amounts such a crumb) can pose a severe health risk for:

A. Short-term sickness including abdominal pain, gas, diarrhea and/or vomiting; and

B. Long-term damage to the small intestine (which affects his ability to absorb nutrients required for proper growth and development), and an increased risk of other medical conditions including, but not limited to, auto-immune thyroiditis, liver disease, inflammatory bowel disease, osteopenia, osteoporosis, cancer (lymphoma),[8] and immunological scarring.[9]

Food Allergies Significantly Impact Psychosocial Well-Being[10] of Children with Food Allergies

For all intents and purposes, Gluten is poison to our grandson's body, and it is analogous to the serious danger that peanuts pose to those who are afflicted with nut allergies. Eating Gluten does not initiate an anaphylactic cascade reaction in Celiac Disease patients. However, the ingestion of Gluten, even accidental ingestion of a trace amount of Gluten, can sicken and endanger (set back) the healing of a patient's small intestine enabled through his/her strict adherence to a Gluten Free diet, and/or trigger new damage to the small intestine that could take additional years to heal. There is no medicine available (i.e., epinephrine pen for nut allergies) to take to treat any accidental ingestion of Gluten. Airlines no longer serve nuts and snacks out of concern and respect for people allergic to nuts, yet there is no corresponding recognition of the effect of gluten on celiac patients. Until our grandson was diagnosed, we had no clue or awareness of the condition and its effects.

According to the CDC, "Many studies have shown that food allergies have a significant effect on the psychosocial well-being of children with food allergies and their families."[11] According to the University of Chicago, "Living healthily with Celiac Disease requires skill in negotiating the everyday environment—especially for children and teens, where most positive social encounters, from school lunches to prom, is organized around food."[12]

Disparities Among Gastrointestinal Disorders in Research Funding From NIH

To understand and correct the historically inadequate NIH funding of Celiac Disease, it is instructive to read the peer reviewed academic analysis published in 2017

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[6] University of Chicago Celiac Disease Center, Facts and Figures, https://www.cureceliacdisease.org/wp-content/uploads/341__CDCFactSheets8__FactsFigures.pdf.

[7] University of Chicago Celiac Disease Center, https://www.cureceliacdisease.org/overview/.

[8] Beyond Celiac, Fast Facts about Celiac Disease Infographic, www.beyondceliac.org , and https://www.beyondceliac.org/60forceliac/Fast-Facts-about-Celiac-Disease-Infographic/1448/.

[9] Celiac Disease Foundation, "Chronic Inflammation Permanently Alters Immune Cells in Celiac Patients," https://celiac.org/about-the-foundation/featured-news/2019/02/chronic-inflammation-permanently-alters-immune-cells-in-celiac-patients/.

[10] Beyond Celiac, Psychosocial Impacts of Celiac Disease Infographic, https://www.beyondceliac.org/60forceliac/Psychosocial-Impacts-of-Celiac-Disease-Infographic/1450/.

[11] U.S. Department of Health and Human Services, Centers for Disease Control and Prevention, "Voluntary Guidelines for Managing Food Allergies in schools and Early Care and Education Programs" (footnotes 39–45), https://www.cdc.gov/healthyschools/foodallergies/pdf/13__243135__A__Food__Allergy__Web__508.pdf.

[12] University of Chicago, 2018 Report, https://www.cureceliacdisease.org/wp-content/uploads/CdC__YearEnd__Report__18__WEB.pdf.

by the American Gastroenterological Association entitled, "Disparities Among Gastrointestinal Disorders in Research Funding From the National Institutes of Health," which found that, out of various Gastrointestinal Disorders:

A. "Celiac disease consistently received the lowest amount of NIH funding over the 5-year period, at approximately $3 million per year."
B. "Celiac disease consistently received the lowest amount of NIH grants, at approximately eight grants per year."
C. "Barrett's esophagus, with a prevalence of approximately 1 percent, received $64.1 million over the 5-year period. Celiac disease, with prevalence very similar to that of Barrett's Esophagus at approximately 1 percent, received significantly less funding over the 5-year period at $15.4 million—the lowest amount of all the diseases studied."
D. "Although there is no global metric for disease importance, it is difficult to justify on medical and scientific bases a reason for such large and persistent funding differences. Although Crohn's disease has many available and emerging treatment options, celiac disease, for example, is more prevalent and has no current treatment available to patients beyond the burdensome gluten-free diet; however, celiac disease received only a small fraction of the funding that Crohn's disease received from the NIH over the 5-year period."
E. "In conclusion, NIH funding of GI diseases is not proportional to disease prevalence or mortality. These data further suggest that a few diseases, including IBS and celiac disease, are underfunded in comparison with other diseases, especially when the prevalence, burden, and available treatment options are considered. Plausible reasons for this disparity include varying numbers of established research programs to recruit young investigators, fewer grants submitted because of a lack of investigators in the field owing to poor funding, and narrow expertise of peer reviewers on NIH review committees. It seems as if the lack of funding becomes a self-fulfilling prophecy—don't allocate more funding because there are not enough investigations going on? In contrast with disorders with low funding levels, ample public and private funding of Crohn's disease allows for excellent research, which in turn, favors more awards of research funding. This may seem circuitous; however, funding of Crohn's disease research provides an example of the way in which success breeds success."[13]

Research in Celiac Disease has lagged behind in the biomedical imagination of other more well NIH funded research diseases, and this has been a vicious cycle adversely impacting the Celiac Disease research ecosystem whereby there have been fewer grant submissions, more limited interest among young researchers as well as very limited funding available from the private and philanthropic sectors. Public funding is perceived as validation of the seriousness of a disease and its research needs. Absent public funding validation, a vacuum is created, which causes private funding to be scarce. In contrast, the NIH funded Crohn's disease research model is an example of "success breeds success" that has created a positive feedback loop (network effects) with ongoing and meaningful government validation, more established research programs recruiting more young investigators, increased grant submissions, increased private sector funding, and increased philanthropic funding.

For fiscal year 2020, we are respectfully requesting that NIH model its funding of Celiac Disease research on its funding model and scale for research on Crohn's Disease. In spite of a lower number of disease specific mortalities as well as many available and emerging treatment options, Crohn's disease received about 40 NIH grants per year averaging about $16 million annually from 2011–2015, in comparison to Celiac Disease which received about 8 NIH grants per year averaging about $3.0 million annually from 2011–2015. In 2018, the NIH RePORT suggests that Celiac Disease research received a modest increase to 13 grants totaling approximately $4.7 million. In contrast, in 2018, NIH research funding for Crohn's disease encompassed 210 grants totaling $69 million.

Notwithstanding the Herculean efforts by some brilliant, small and under resourced research teams and advocacy groups, the paucity of NIH funding has created a vacuum and stifled innovation in the efforts to treat and cure Celiac Disease. This can change in fiscal year 2020 with meaningful NIH funding that validates research ready initiatives at multi-institute translational research centers including at the University of Chicago Celiac Disease Center, Celiac Disease Center at Columbia

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[13] "Disparities Among Gastrointestinal Disorders in Research Funding From the National Institutes of Health," The American Gastroenterological Association, By: Emma Clerx, Harvard University; Sonia Kupfer, Celiac Disease Center at University of Chicago; and Daniel Leffler, North American Society for the Study of Celiac Disease, Beth Israel Deaconess Medical Center; September 4, 2017, https://www.gastrojournal.org/article/S0016-5085(17)36084-5/pdf.

University, the Harvard Medical School Celiac Research Program and the Children's Hospital of Philadelphia Center for Celiac Disease.

PREPARED STATEMENT OF THE NATIONAL ALLIANCE FOR CAREGIVING

Chairman Blunt and Ranking Member Murray, I respectfully submit this testimony today on behalf of the nearly 44 million Americans who provide support to people living with chronic health conditions, medical complexity, disabilities, or other long-term care needs as family caregivers.[1] The National Alliance for Caregiving proposes the following support:

- —Support for the Older Americans Act Title III, Part E National Family Caregiver Program, administered by the Administration for Community Living and the Administration on Aging as follows: (a) an increase of 20 percent to $226 million for the National Family Caregiver Support Program; (b) an overall increase of at least 12 percent for other parts of the OAA Title III; and (c) an increase of at least 12 percent increase for Title VI, Part C, the Native American Caregiver Support Program.
- —Additional, modest funding for the "Recognize, Assist, Include, Support, and Engage Family Caregivers Act of 2017" (RAISE Family Caregivers Act).
- —Create a National Resource Center on Family Caregiving under the Administration for Community Living with annual funding of at least $500,000.

Estimates indicate that if we were to replace each family caregiver, friend, or neighbor, with a paid direct care worker, it would cost our economy $470 billion annually.[2] This care, while typically provided without financial support, is not without cost.

Since 1996, the National Alliance for Caregiving has worked to identify credible policy solutions that work for individuals as well as the public and private sectors of the United States. We conduct public policy research across the lifespan. We provide technical assistance to a virtual network of State/local caregiving advocates representing over 27 communities. We are also the founder and Secretariat for the International Alliance for Carer Organizations (IACO), where we join 16 other nations represented by nonprofit organizations around the world to determine how to better support the contributions of caregivers to our societies. It is with this background that we request the following support.

I. SUPPORT FOR THE OLDER AMERICANS ACT

The Older Americans Act offers the most comprehensive support for family caregivers of adults. The program provides grants to States and territories to create innovative programs to empower caregivers to care for their families at home for long as possible. By providing information, counseling, training, respite care, and services the program reduces caregiver depression, anxiety, and stress, enables caregivers to provide care longer and thereby avoiding or delaying the need for costly hospital and institutional care. Given the aging of America and shrinking family sizes, we respectfully request: (1) an increase of 20 percent to $226 million for the National Family Caregiver Support Program under Title III, Part E of the Older Americans Act and administered by the Administration for Community Living; (2) an overall increase of at least 12 percent for other parts of the OAA Title III, which provide many of the supports and services on which both older adults and their caregivers rely, such as respite services, adult day care and much more; and (3) an increase of at least 12 percent increase for Title VI, Part C, the Native American Caregiver Support Program.

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[1] In general, when NAC uses the term "family caregiver," we rely on the definition from the recently enacted RAISE Family Caregivers Act, which describes a caregiver as "an adult family member or other individual who has a significant relationship with, and who provides a broad range of assistance to, an individual with a chronic or other health condition, disability, or functional limitation." From Public Law No: 115–119, available at https://www.congress.gov/bill/115th-congress/house-bill/3759. In research and in advocacy, "caregiver" may be described as: informal caregiver, care partner, caretaker, and related terminology. In an international context, the term "carer" is often used. It should be noted that an estimated 1.4 million children in the U.S. are unpaid caregivers (NAC and United Hospital Fund, Young Caregivers in the U.S. (2005) at https://www.caregiving.org/data/youngcaregivers.pdf).

[2] Reinhard, S., Feinberg, L. F., Choula, R., & Houser, A., Valuing the Invaluable 2015 Update: Undeniable Progress, but Big Gaps. (2015), at https://www.aarp.org/ppi/info-2015/valuing-the-invaluable-2015-update.html.

II. CONTINUED SUPPORT FOR THE RAISE FAMILY CAREGIVERS ACT

To date, the Advisory Committee for this Act has yet to convene publicly, and as we approach the law's anticipated sunset in 2021, we request additional, modest funding that will allow this initiative to continue toward a meaningful national strategy for caregivers. The momentum we see in other communities—cancer, Alzheimer's and dementia—has come from a unified national strategy with clearly identified goals for the community through like committees such as the National Alzheimer's Project Act Advisory Committee.

III. CREATION OF A NATIONAL RESOURCE CENTER ON FAMILY CAREGIVING

To that same effort, under the auspices of the Administration for Community Living, we ask that the Subcommittee direct the Assistant Secretary for Aging to establish and operate through a grant or contract a National Resource Center on Family Caregiving with annual funding of at least $500,000. This Center would conduct research; provide training, technical assistance, and information to State and local programs; analyze policy, programs and practices and share best practices with the aging network; and provide support to the National Family Caregiver Support Program. Activities could promote quality and improvement in the support provided to family and other informal caregivers of older individuals, including for rural caregivers and caregivers for those with cognitive impairment such as dementia.

The National Resource Center on Family Caregiving could align information about existing support and resources for family caregivers and reduce inefficiencies in Federal programs. For example, some programs support caregivers only via the beneficiary (such as the Medicaid Home-and-Community-Based Waivers programs) and others support the caregiver directly without connection to the health or social care system they support (such as the National Family Caregiver Support Program and the Lifespan Respite Programs).

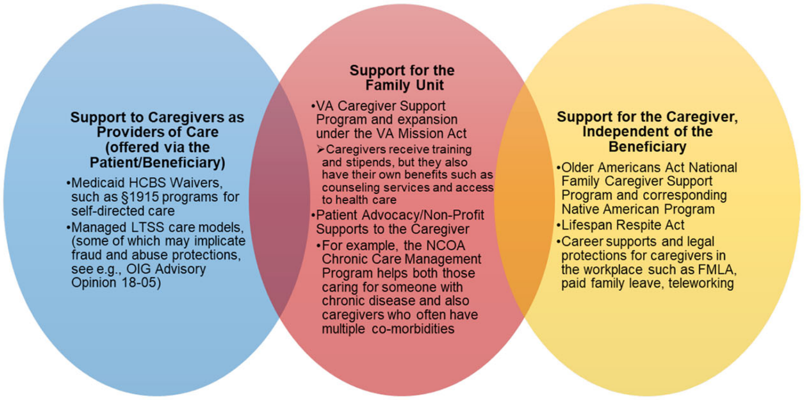

Figure 1: Examples of the Three Siloes of Caregiver Support

WHEN SUPPORTED, FAMILY CAREGIVERS IMPROVE POPULATION HEALTH AND REDUCE SYSTEMS COSTS

Decades of research make clear that family caregivers are the predominant providers of long-term services and supports to older adults and persons with disabilities of all ages. More than half (57 percent) of America's caregivers provide medical/nursing to individual patients, through medical/nursing tasks such as giving injections, tube feedings, catheter and colostomy care, and other complex care responsibilities often without prior training or support.[3] Many caregivers help with managing medication (46 percent) and transportation (78 percent). Many caregivers have financial, emotional, and psychosocial costs that impact their ability to provide care and to continue self-care. Caregivers often face high out-of-pocket costs at an

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[3] Id.

average of $7,000 per year, with a higher strain on African American and Latino families.[4] While the need for caregivers increases, the number of available caregivers is in decline—precisely when their services are needed now more than ever.[5]

When family caregivers receive support, we know they can be active partners in lowering health system costs, improving quality of care, and improving the health of populations. For example, academic research has shown that caregivers can reduce avoidable hospital readmissions in discharge from hospital to home by 25 percent at 90 days and 24 percent at 180 days.[6] For medically complex conditions, such as dementia, caregivers can help an older adult to live longer in the community and delay the costs of institutionalization.[7] Caregivers support the aims of health reform and prevent an overmedicalization of our society—allowing the people closest to us to provide care as we age and manage disease.

Thank you for the opportunity to provide testimony to the Subcommittee.

[This statement was submitted by C. Grace Whiting, J.D., President and CEO, National Alliance for Caregiving.]

PREPARED STATEMENT OF NATIONAL ALLIANCE FOR EYE AND VISION RESEARCH

EXECUTIVE SUMMARY

NAEVR, on behalf of the vision community, thanks Congress, especially the House and Senate Appropriations Subcommittees on Labor, Health and Human Services, and Education (LHHS), for strong bipartisan support for the National Institutes of Health (NIH) funding increases from fiscal year 2016 through fiscal year 2019. The $9 billion increase has helped the agency regain ground lost after years of effectively flat budgets. In fiscal year 2020, NAEVR urges Congress to appropriate at least $41.6 billion for NIH, a $2.5 billion or 6.4 percent increase over the fiscal year 2019 program level. This increase would allow for meaningful growth above inflation in the base budget to support promising science across all Institutes and Centers (I/Cs), as well as ensure that funding from the Innovation Account established through the 21st Century Cures Act would supplement NIH's base budget, as intended, through dedicated funding for specific programs.

With respect to I/C funding, NAEVR thanks the Senate Subcommittee for its past efforts to ensure inflationary increases. For fiscal year 2020, NAEVR urges Congress to appropriate at least $850 million for the National Eye Institute (NEI), a $53 million or 6.4 percent increase over enacted fiscal year 2019. This would allow for biomedical inflation of 2.8 percent plus meaningful growth. Despite the total fiscal year 2016–2019 funding increases of $120 million, NEI's fiscal year 2019 enacted budget of $797 million is just 14 percent greater than the pre-sequester fiscal year 2012 budget of $702 million. Averaged over the seven fiscal years, the 2 percent annual growth rate is less than the average annual biomedical inflation rate of 2.8 percent, thereby eroding purchasing power.

The NEI, which just concluded the 50th anniversary of its creation by Congress in 2018, is the world leader in sight-saving and vision-restoring research. Congress must ensure robust NEI funding to address the challenges of The Decade of Vision 2010–2020—as recognized by Congress in S. Res. 209 in 2009—which include an aging population, disproportionate risk/incidence of eye disease in fast-growing minority populations, and the visual impact of numerous chronic diseases and their therapies.

We must maintain the momentum of vision research since vision health is vital to overall health and quality of life. Since the United States is a world leader in vision research and in training the next generation of vision scientists, the very health of the global vision research community is at stake.

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[4] See Family Caregiving and Out-of-Pocket Costs: 2016 Report, AARP, available at https://www.aarp.org/content/dam/aarp/research/surveys__statistics/ltc/2016/family-caregiving-costs.doi.10.26419%252Fres.00138.001.pdf.

[5] Eldercare Workforce Alliance. (2011). "3.5 Million Workers Needed by 2030 to Care for Older Adults, Current Levels of Workforce Already Stretched." Available at: https://eldercareworkforce.org/newsroom/press-releases/article:3–5-million-workers-neededby-2030-to-care-for-older-adults-current-levels-of-workforce-already-stretched/.

[6] Rodakowski, et al. "Caregiver Integration During Discharge Planning for Older Adults to Reduce Resource Use: A Metaanalysis," Journal of the American Geriatric Society (April 2017), at http://onlinelibrary.wiley.com/doi/10.1111/jgs.14873/full.

[7] See e.g., Mittleman, et al. "An intervention that delays institutionalization of Alzheimer's disease patients: treatment of spouse-caregivers," Gerontologist (1993), https://www.ncbi.nlm.nih.gov/pubmed/8314099.

NEI LEADS IN GENETIC AND REGENERATIVE MEDICINE RESEARCH

As recently as a March 21, 2018, NEI 50th Anniversary Congressional Reception, NIH Director Francis Collins, MD, PHD stated the following about the NEI:

> "Due to the architecture, accessibility, and the elegance of the eye, vision research has always been a few steps ahead in biomedical research. Understanding the genetic basis of eye diseases has led the way for understanding the genetic basis of many common diseases."

The NEI has been a leader in genetics/genomics research and regenerative medicine.

Genetics/Genomics:

—Vision researchers worldwide participating in NEI's Glaucoma Genetics Collaboration Heritable Overall Operational Database (NEIGHBORHOOD) Consortium have identified 133 genetic variants that predict within 75 percent accuracy a person's risk for developing glaucoma related to elevated intraocular pressure (IOP). Among the 133 variants, 68 had not been previously linked to IOP, and their loci point to cellular processes, such as lipid metabolism and mitochondrial function, that contribute to IOP. By understanding these cellular processes that can increase IOP and cause optic nerve damage, clinicians may be able to make an earlier diagnosis and researchers may be able to develop neuroprotective therapies to potentially halt disease progression.

—NEI-funded research has also made discoveries of dozens of rare eye disease genes possible, including the discovery of RPE65, which causes congenital blindness called Leber congenital amaurosis (LCA). In late 2017, based on NEI's initial efforts, the Food and Drug Administration (FDA) approved a gene therapy for this condition. These gene-based discoveries are forming the basis of new therapies that treat the disease or potentially prevent it.

Regenerative Medicine:

—NEI is at the forefront of regenerative medicine with its Audacious Goals Initiative in Regenerative Medicine Initiative (AGI), which launched in 2013 with the goal of restoring vision. Initially asking a broad constituency of scientists within the vision community and beyond to consider what could be done if researchers employed this new era of biology, the AGI currently funds major research consortia that are developing innovative ways to image the visual system. Researchers can now look at individual nerve cells in the eyes of patients in an examination room and learn quite directly whether new treatments are successful. Another consortium is identifying biological factors that allow neurons to regenerate in the retina. And the AGI is gathering considerable momentum with current proposals to develop disease models that may result in clinical trials for therapies within the next decade.

—NEI plans a first-in-human clinical trial that would test a stem cell-based therapy from induced pluripotent stem cells (iPSC) to treat geographic atrophy, also known as the "dry" form of Age-related Macular Degeneration (AMD), the leading cause of vision loss among people age 65 and older. This trial converts a patient's own blood cells to iPS cells which are then programmed to become retinal pigment epithelial (RPE) cells, which nurture the photoreceptors necessary for vision and which die in geographic atrophy. Bolstering remaining photoreceptors, the therapy replaces dying RPE with iPSC-derived RPE.

THE NATION'S INVESTMENT IN THE NEI RESULTS IN NEW THERAPIES TO TREAT MAJOR EYE DISEASES

Speaking after Dr. Collins at the March 21, 2018, NEI 50th anniversary Congressional Reception, NEI Director Paul Sieving, MD, PhD observed that:

> "As we look back 50 years, we remember times when people had untreatable eye diseases. These included AMD, diabetic retinopathy, and glaucoma. These were blinding conditions, and doctors had little more than hope to offer patients."

The Federal commitment—made in 1968 when President Lyndon Johnson signed legislation creating the NEI—has made possible treatments and therapies for the very diseases that Dr. Sieving cited as previously resulting in blindness or severe vision loss:

—*AMD:* The treatment of the "wet" form of AMD has made great strides resulting from use of Anti-Vascular Endothelial Growth Factor (VEGF) therapies. Last year, the NEI launched the AMD Ryan Initiative Study (ARIS), a prospective international study of patients that uses the latest advances in retinal imaging to identify biomarkers of the disease and targets for early therapeutic interventions.

—*Diabetic Retinopathy:* Over the span of nearly 50 years, NEI has funded a number of randomized controlled trials (RCTs), which have led to major vision health improvements. In the 1960s, about half of patients with diabetic retinopathy were blind within 5 years of diagnosis. NEI-sponsored clinical trials-starting in the early 1970s with the Diabetic Retinopathy Study and most currently with the Diabetic Retinopathy Clinical Research Network-have reduced the incidence of severe vision loss from diabetic retinopathy by 90 percent.

—*Glaucoma:* As IOP appears to be the overriding factor that that determines whether someone develops glaucoma, NEI research into primary open-angle glaucoma (POAG), the most common form of the disease, has resulted in two FDA-approved drug therapies that add to those that have already emerged from NEI research. Targeting the eye's trabecular meshwork-which is one of the pathways responsible for regulating fluid flow within the eye-the new generation of therapies reflects an expanding menu of drugs, potentially in combination therapy, that lower IOP and better meet the needs of patients.

Critical to the diagnosis and monitoring of treatments for these eye diseases is Optical Coherence Tomography (OCT), which is a non-invasive, high-resolution imaging technology that displays a three-dimensional cross-sectional view of the layers of the retina. Developed over 25 years with $423 million in NIH and National Science Foundation (NSF) funding, OCT has enabled better personalization of eye care to facilitate more efficient use of effective but costly drug therapies. A December 2017 American Journal of Ophthalmology article reported that OCT saved Medicare $9 billion and patients $2.2 billion in co-pays by reducing unnecessary injections. As the technology continues to be applied to new medical conditions, such as Alzheimer's disease and Parkinson's disease, it supports a private commercial market of $1 billion and more than 16,000 high-paying jobs. https://doi.org/10.1016/j.ajo.2017.09.027.

CONGRESS MUST ROBUSTLY FUND THE NEI AS IT ADDRESSES THE INCREASING BURDEN OF VISION IMPAIRMENT AND EYE DISEASE

NEI's fiscal year 2019 enacted budget of $797 million is just 0.55 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. Of the $717 billion annual cost of vison 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 $2.40 per-person, per-year for vision research, while the cost of treating low vision and blindness is at least $6,680 per-person, per-year. [http://costofvision.preventblindness.org/]

In a May 2016 JAMA Ophthalmology article, NEI-funded researchers reported that the number of people with legal blindness will increase by 21 percent each decade to 2 million by 2050, while best-corrected visual impairment will grow by 25 percent each decade, doubling to 6.95 million people—with the greatest burden affecting those 80 years or older. [http://jamanetwork.com/journals/jamaophthalmology/article-abstract/2523780?resultClick=1]

In an August 2016 JAMA Ophthalmology article, the Alliance for Eye and Vision Research (AEVR, NAEVR's educational foundation) reported that a majority of Americans across all racial and ethnic lines describe losing vision as having the greatest impact on their day-to-day life. Other studies have reported that patients with diabetes who are experiencing vision loss or going blind would be willing to trade years of remaining life to regain perfect vision, since they are concerned about their quality of life. [http://jamanetwork.com/journals/jamaophthalmology/article-abstract/2540516?resultClick=1]

Investing in vison health is an investment in overall health. NEI's breakthrough research is a cost-effective investment, since it leads to treatments and therapies that may delay, save, and prevent healthcare expenditures. It can also increase productivity, help individuals to maintain their independence, and generally improve the quality of life—as vision loss is associated with increased depression/accelerated mortality.

Congress demonstrated strong support for vision research with the creation of the NEI and recognition this past year of its accomplishments and current/future challenges. Without robust funding, however, the NEI may not be able to fund breakthrough research and to continue U.S. leadership in vision research and training.

In summary, NAEVR requests fiscal year 2020 NIH funding of at least $41.6 billion and NEI funding of $850 million.

NAEVR, which serves as the "Friends of the NEI," is a 501(c)4 non-profit advocacy coalition comprised of 50-plus 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.

PREPARED STATEMENT OF THE NATIONAL ALLIANCE FOR PUBLIC CHARTER SCHOOLS

Mr. Chairman and Members of the Subcommittee, I am pleased to present the views of the National Alliance for Public Charter Schools on the fiscal year 2020 appropriation for the Charter Schools Program (CSP) operated through the U.S. Department of Education. I thank the Members for increasing the CSP appropriation from $400 million in fiscal year 2018 to $440 million in fiscal year 2019. The CSP plays a crucial role in expanding educational options for families and in improving public school outcomes nationwide. For fiscal year 2020, the National Alliance endorses the Administration's request of $500 million for the CSP. At a $500 million funding level, we concur with the Administration that, given the current needs of charter schools, up to $125 million should be available for charter school facilities, through the Credit Enhancement and State Facilities Incentive Grants programs. This amount would help put significant resources towards meeting the demand for adequate facilities for all charterschools, a need we are seeing more and more as the public charter sector matures and evolves. Further, we recommend that the appropriation allow up to $150 million to be available for grants to charter management organizations (CMOs) for the replication and expansion of effective charter models, strengthening another important element of the CSP. We request that the appropriation provide for these allocations, rather than adhering strictly to the authorizing statute, consistent with the Appropriations Committees' approach over many years.

Demand for seats in public charter schools continues to significantly exceed supply. In fact, surveys indicate that some 3.3 to 5.3 million additional students would attend a charter school if space were available in a convenient location. The increase we are recommending for the CSP would not meet the entire demand for charters, but it would enable continued progress in providing academic options and opportunity to the some of the Nation's most disadvantaged students.

THE GROWTH OF PUBLIC CHARTER SCHOOLS AND THE IMPACT OF CSP

The first charter school opened in 1992 and today more than 7,000 public charter schools operate in 44 States, the District of Columbia, Puerto Rico, and Guam, serving approximately 3.2 million PreK—12 students. Between the fall of 2016 and the fall of 2017, more than 300 new charter schools opened across the country and total enrollment grew by more than 150,000 students. Charter schools now enroll some 6 percent of K–12 students nationally. We estimate that the CSP provided start-up, replication, or expansion funds to 60 percent of all charter schools that opened between school years 2006–2007 and 2013–2014. The charter school sector could not have grown and prospered as it did without this Federal support.

CHARTER SCHOOL PERFORMANCE

The charter school movement has been a leader in driving innovation, providing students and families with wider choices within the public school system, and producing results. Our schools have demonstrably narrowed achievement gaps, increased graduation rates, and helped revitalize communities. As in any other area of education, not all charter schools have been equally effective, and, by design, States and charter school authorizers have closed the failing ones. But numerous studies demonstrate that the charter school movement, considered as a whole, has been a large net plus for America's students.

For example, a major study, completed in 2015 by the Center for Research on Education Outcomes (CREDO) at Stanford University, covering 41 urban communities in 22 States, found:

—Charter school students gained 40 additional days of learning in math and 28 days in reading per year, compared to their peers in non-charter public schools.

—Four or more years of enrollment in an urban charter school resulted in 108 additional days of learning in math and 72 days in reading, compared to non-charter public schools.

—In urban charter schools, low-income Hispanic students gained 48 additional days or learning per year in math and 25 days in reading. Low-income African-American students gained 59 days in math and 44 days in reading. Hispanic students who were identified as English learners gained 72 additional days in math and 79 in reading.

Other studies have also reported very positive findings.

CHARTER SCHOOL FACILITIES NEEDS

As I noted earlier, the National Alliance endorses the Administration's proposal that up to $125 million of the fiscal year 2020 appropriation be available for the two CSP programs that address charter school facilities needs: Credit Enhancement for Charter School Facilities and the State Facilities Incentive Grants (SFIG). These programs take complementary approaches to addressing what is often a significant barrier to a charter school opening and serving children.

Our schools have generally not had access to the funding sources that support the facilities needs of other public schools, such as municipal bonds, property tax revenues, and State school facilities programs. They have had to scrape by in buildings not designed for learning, or use funds to meet facilities needs that should have been available for academics, or they simply never open at all, only for lack of an adequate building. Access to buildings is also a significant impediment to charter school growth and reaching students in underserved communities. Unlike most Federal programs, Credit Enhancement and SFIG also generate additional funding: Credit Enhancement leverages $16 for every Federal dollar invested andhe Incentive Grants require a State match.

THE NEED FOR MORE FLEXIBLE APPROPRIATIONS LANGUAGE

The National Alliance is aware that ED is working with the appropriators on reallocation of some of the fiscal year 2019 CSP appropriation, an issue that arose when a few of the larger States, which had been expected to apply under the State Entities program, did not apply for fiscal year 2019 awards. Under the authorizing act, the Department must hold a new State Entities competition each year, even though the number of States that will be ready for a new grant in a particular year will vary greatly. If the estimates are off, there can be too little or too much money appropriated for the program. What happened this year does not mean the demand for the

State Entities program has diminished. Rather, we believe that what happened calls for making the appropriations language flexible, giving ED some room to allocate funds in response to shifts in the number of States applying from year to year. We recommend that the appropriators provide that flexibility in the fiscal year 2020 appropriation, as it has in prior years, by only specifying floors or ceilings for the CMO program and facilities programs.

CONCLUSION

The National Alliance takes pride in the accomplishments of public charter schools over the past quarter century. The successes of charter school could not have been achieved without the CSP, which continues to be a vital source of support for creating high-quality charter schools, ensuring the availability of adequate and helping us to meet more of the demand. Toward those ends, we urge the Congress to provide a $500 million appropriation for the CSP in fiscal year 2020.

[This statement was submitted by Nina Rees, President and CEO, National Alliance for Public Charter Schools.]

PREPARED STATEMENT OF THE NATIONAL ALLIANCE ON MENTAL ILLNESS

Chairman Blunt, Ranking Member Murray and distinguished members of the Subcommittee, on behalf of NAMI, the National Alliance on Mental Illness, I am pleased to offer our views on the Subcommittee's fiscal year 2020 bill. NAMI is the Nation's largest grassroots mental health organization dedicated to building better lives for the millions of Americans affected by mental illness. NAMI advocates for improved research and innovation, increased access to care, and comprehensive services and supports for individuals living with mental health conditions.

HIGH COST OF MENTAL ILLNESS IN AMERICA IN THE U.S.

Approximately 1 in 5 Americans live with a mental health condition—approximately 46.6 million people in 2017.[1] Individuals who live with mental health conditions are our neighbors, family members, and friends. They contribute to all sectors of the U.S. economy—yet the social and economic costs associated with mental health conditions is devastating. According to a 2016 study, mental illness topped the list of the costliest conditions in the U.S. at $201 billion in 2013, the year examined.[2] While this financial cost is an incredible burden on U.S. healthcare spending, the personal cost of untreated mental illness to individuals and families is much more devastating. At NAMI we hear from countless individuals who share their own stories of a family member or friend who couldn't reach their full potential because of a lack of necessary, innovative treatment. Some also carry the burden of someone lost to suicide. In fact, each year 47,173 Americans die by suicide, and it's currently the 10th leading cause of death in the United States.[3] Additionally, in 2015, suicide and self-injury cost the U.S. $69 billion.[4] As you can see, the work of this Subcommittee and your commitment to adequate investment in innovative mental health research, and first-class treatments and supports is vitally important to keep America strong and save American lives.

FISCAL YEAR 2019 LABOR-HHS APPROPRIATIONS BILL

NAMI would like to thank the Chairwoman, Ranking Member, and Subcommittee for the bipartisan effort on the fiscal year 2019 enacted bill, and the critical investments that were made for mental health research and treatment. We are especially grateful for the $2 billion budget increase for the National Institutes of Health (NIH), the $101 million increase for the National Institute of Mental Health (NIMH), the $29 million increase for the BRAIN Initiative, and the $86 million increase for the All of Us precision medicine study. NAMI is also very appreciative of the additional $150 million for the ongoing Certified Community Behavioral Health Clinics (CCBHCs).

In order to build on this progress, it is imperative for Congress to come to a two-year budget agreement to lift the current Budget Control Act (BCA) caps on Non-Defense Discretionary (NDD) spending to avoid any future threat of sequestration. In the absence of an agreement, the limits of NDD spending will drop to unsustainable levels and will result in deep cuts to mental illness research and services.

NAMI FISCAL YEAR 2020 FUNDING PRIORITIES FOR THE NATIONAL INSTITUTE OF MENTAL HEALTH

As a member of the Ad Hoc Group for Medical Research Funding, NAMI endorses the goal of at least $41.6 billion for the National Institutes of Health (NIH), a $2.5 billion increase in base funding for the agency. Additionally, NAMI supports the current NIMH strategic plan and its high-level strategic objectives.

Advancing Services and Intervention Research & Investing in Early Psychosis Prediction and Prevention (EP3)

Approximately 100,000 young Americans experience a first episode of psychosis (FEP) each year. Intervening early is critical to altering the downward trajectory associated with psychosis. Accordingly, NAMI prioritized support for the NIMH Recovery After an Initial Schizophrenia Episode (RAISE) Project, which developed Coordinated Specialty Care (CSC) programs that are helping people experience recovery. We urge further investment into maintaining CSC's positive treatment and quality-of-life outcomes over the long-term. NAMI also supports NIMH's Early Psychosis Prediction and Prevention (EP3) initiative, which shows promise in detecting risk for psychotic disorders and reducing the duration of untreated psychosis in adolescents who have experienced early psychosis.

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[1] Gordon, J. (2018, May 15). National Institute of Mental Health. Prevalence of Mental Illness. Retrieved from: https://www.nimh.nih.gov/health/statistics/mental-illness.shtml. Date: 3 April 2019.

[2] Roehrig, C. Mental Disorders Top The List of The Most Costly Conditions in The United States: $201 Billion, Health Affairs, 2016. DOI:10.1377/hlthaff.2015.1659.

[3] Suicide Statistics. American Foundation for Suicide Prevention. Retrieved from: https://afsp.org/about-suicide/suicide-statistics/. Date: 2 April 2019.

[4] Ibid.

Advancing Precision Medicine

NAMI remains supportive of the NIMH Research Domain Criteria (RDoC) and its efforts to build a classification system based on underlying biological and behavioral mechanisms, rather than on symptoms. Through continued development, we believe RDoC will provide the precision currently lacking in traditional diagnostic approaches to mental health conditions.

NAMI FISCAL YEAR 2020 FUNDING PRIORITIES FOR SAMHSA PROGRAMS

NAMI supports programs at the Center for Mental Health Services (CMHS) at SAMHSA that are focused on replication and expansion of effective, evidence-based interventions to serve children and adults living with mental health conditions. We are grateful for increases in recent years for the Community Mental Health Services Block Grant (MHBG) to its current level of $722.6 million.

Additionally, NAMI strongly supports the 10 percent set-aside in the MHBG for evidence-based programs that address the needs of individuals with early serious mental illness. As noted above, NAMI endorses the Coordinated Specialty Care (CSC) model for collaborative, recovery-oriented care. This evidence-based approach emphasizes shared decisionmaking and should be the priority program for receiving funding from this set-aside.

Request for Consideration of additional set-aside for Crisis Care Services

As the Subcommittee is aware, there is an increased need for mental health crisis care services to improve our Nation's mental health and combat the suicide and opioid epidemics. As such, NAMI has submitted a funding request for an additional $35 million to the MHBG to fully-fund a 5 percent set-aside for Crisis Care Services. If funded, we request the array of crisis care services to include centrally deployed 24/7 mobile crisis units, short-term residential crisis stabilization programs, the implementation of evidence-based protocols for treating individuals at risk of suicide, and regional or statewide crisis call centers coordinating in real time.

Additional NAMI fiscal year 2020 funding priorities at CMHS

We support continued funding for all current programs at CMHS, including $125 million for Children's Mental Health Services, $14.3 million for Criminal and Juvenile Justice Programs, $71 million for Project AWARE State grants, $64.4 million for the Projects for Assistance in Transition from Homelessness (PATH) program, $33.4 million for the Treatment Systems for Homeless portfolio, and $15 million each for the continuation of the Assisted Outpatient Treatment (AOT) pilot program and Assertive Community Treatment (ACT) program. NAMI respectfully requests the Subcommittee consider a $68 million increase to the National Suicide Prevention Lifeline, for a total of $80 million and fully fund all Garrett Lee Smith (GLS) suicide prevention grants consistent with fiscal year 2019, enacted. Additionally, NAMI is concerned about the proposed elimination of the Primary and Behavioral Health Care Integration (PBHCI) program in the fiscal year 2020 President's Budget (PB) Request. The PBHCI is a critical program which supports collaboration and infrastructure that increases primary and wellness care for children and adults with serious mental health conditions, and we strongly encourage the restoration of funding at $51.9 million.

Health Resources and Services Administration (HRSA)

NAMI recognizes the important work of HRSA, and therefore requests $36.9 million for Mental and Behavioral Health, $75 million for the Behavioral Health Workforce, and $10 million for Increasing Access to Pediatric Mental Health Care-all level to fiscal year 2019, enacted funding. These programs are crucial to supporting development of the mental health workforce.

Fully Funding the 21st Century Cures Act

The Helping Families in Mental Health Crisis Act as included in the 21st Century Cures Act, Public Law 114–255 was a landmark piece of legislation and represented a substantial leap forward for Americans who live with mental illness. NAMI respectfully asks the Subcommittee to fully fund all programs authorized including $6 million for Adult Suicide Prevention programs and $2.5 million for Strengthening Community Crisis Response Systems. These programs, if funded, will ensure we can capitalize on the advancements put forth in this bill, and will help more Americans living when mental health conditions realize recovery is possible.

CONCLUSION

NAMI would like to express our gratitude to the Chairman, the Ranking Member and the Subcommittee for your investments in the necessary research, treatments, services and supports for Americans living with mental health conditions.

[This statement was submitted by Angela Kimball, Acting Chief Executive Officer, National Alliance on Mental Illness.]

PREPARED STATEMENT OF THE NATIONAL AREA HEALTH EDUCATION CENTERS ORGANIZATION

Chairman Blunt, Ranking Member Murray, and distinguished members of the Subcommittee, thank you for the opportunity to provide testimony on behalf of the National AHEC Organization (NAO). The NAO is the professional organization that represents Area Health Education Centers (AHECs) across the country. We support advances in the AHEC Network to improve health by leading the Nation in recruiting, training, and retaining members of a diverse health workforce in underserved communities. As a member of the Health Professions and Nursing Education Coalition (HPNEC), NAO is pleased to recommend $690 million for the health professions training programs under Title VII and VIII of the Public Health Service Act that are administered by the Health Resources and Services Administration (HRSA). Of this amount, the NAO recommends $67 million in fiscal year 2020 for the Area Health Education Centers program.

The AHEC program was originally authorized at the same time as the National Health Service Corps (NHSC) in 1971. The originating legislation sought to provide primary care providers for Community Health Centers (CHCs) and other direct providers of healthcare services for underserved areas and populations. The creators of the legislation that fostered the AHECs intended for AHECs to be the vehicle to recruit health providers into primary healthcareers, diversify the workforce, and develop a passion for service to the underserved in these future providers. Today, as intended, AHECs develop and support the community based training of health professions students in rural and underserved areas. With more than 300 AHECs serving nearly 85 percent of all the counties in the United States and the District of Columbia, the AHEC network recruits a diverse and broad range of students into healthcareers and provides continuing education resources that improve the quality of community-based healthcare for underserved populations and areas. Nationwide, over 358,797 students and health professionals participated in our healthcareer opportunities last year. Our training sites included 3,561 primary care settings, 3,968 sites in medically underserved communities, and 2,620 sites in rural areas. The AHEC network is enabled to successfully perform these education and training services through its collaborative partnerships with CHCs, the NHSC, Rural Health Clinics, Critical Access Hospitals, Tribal Health Centers, and State and local public health departments.

The AHEC network is a part of an critical pipeline that fuels the recruitment, training, distribution, and retention of a national health workforce. At a time where the Association of American Medical Colleges projects our Nation to have a shortage of nearly 120,000 physicians by 2030, AHECs stands as a central access points in meeting this demanding shortage area. Primary care practitioners are the front-line in prevention of disease and providing cost savings in the United States healthcare system. In recognizing this, the AHEC program engages in pre-pipeline, pipeline, and post-pipeline activities that guide individuals through healthcareers pathways and beyond, with a special emphasis on primary care doctors. In 2018, AHECs introduced nearly 183,090 students, ranging from high school to collegiate status, to careers in the health professions and health workforce. The AHEC network facilitated 331.706 rotations and 1,430 residency rotations. Through training in our AHECs 20,000 students were placed in rural and underserved communities and of this number 11,559 medical students, 4,021 were associated health professions students, 3,936 were nursing students, 384 were dental students, and 100 studied behavioral health. Additionally AHECs were responsible for training 144,001 professionals through our continuing education programs. It is these facts that make AHECs integral in the recruitment, training, and retention of the primary care workforce.

AHECs have a continual focus on improving the healthcare system by working with 120 medical schools, 600 nursing and allied health schools, healthcare settings like CHCs, behavioral health practices, and community-based organizations across the Nation. Through these longstanding partnerships, the AHECs employ traditional and innovative approaches to develop and train a diverse healthcare workforce prepared to deliver culturally appropriate, high-quality, team-based care for rural and underserved communities.

One such innovative program is AHEC Scholars, launched in 2018 to address healthcare quality in rural and underserved areas by using interdisciplinary curricula to implement a defined set of clinical, didactic, and community-based activities. Spanning 2 years, AHEC provides its Scholars with 160 hours of experiential and didactic education to supplement their program's curricula. The educaton focuses on six vitally important core topic areas: interprofessional education, behavioral health integration, social determinants of health, cultural competency, practice transformation, and current/emerging health issues. AHECs are embedded in the communities they serve, positioning them to respond rapidly to emergent training needs of health professionals, health professions students, and inter-professional teams on issues associated with natural disasters, disease outbreaks (e.g. Zika), and substance use disorders.

Chairman Blunt, thank you and the committee for the opportunity to present the views of the National AHEC Organization. Allow me to re-emphasize the funding request of $67 million for the Area Health Education Centers program. As the committee finalizes its recommendation the NAO stands ready as resource.

[This statement was submitted by Dwain Harris, Chief Executive Officer, National Area Health Education Centers Organization.]

PREPARED STATEMENT OF THE NATIONAL ASSOCIATION FOR STATE COMMUNITY SERVICES PROGRAMS

As Executive Director of the National Association for State Community Services Programs (NASCSP), I am pleased to submit testimony in support of the Department of Health and Human Services' (HHS) Community Services Block Grant (CSBG). We are seeking a fiscal year 2020 appropriation level of $775 million for CSBG. NASCSP believes that this funding level will ensure that States and local communities have the resources they need to lead the fight against poverty through innovative, effective, and locally tailored anti-poverty programs that help communities, individuals, and families achieve economic security.

NASCSP is the member organization representing the State CSBG Directors in all 50 States, Washington D.C., and 5 U.S. territories on issues related to CSBG and economic opportunity. NASCSP also provides training and technical assistance to help State Offices implement program management best practices and develop evidence-based policy. The State Offices represented by our organization would like to thank the members of this committee for their support of CSBG over the years, particularly in the fiscal year 2019 Labor-HHS Bill.

CSBG is a model example of a successful Federal-State-Local partnership, a fact I can personally attest to having worked for 20 years in various roles within the CSBG network. However, CSBG is arguably one of the most misunderstood programs within the Federal Government. CSBG is often confused with other programs and there is substantial misinformation about how the program operates. I would like to highlight three main points in my testimony:

1. The structure of CSBG empowers States and local communities to take the lead on poverty.
2. The robust local, State, and Federal accountability measures of the CSBG Performance Management Framework are unique and bold compared to other Federal programs.
3. CSBG creates impact in communities across the country by leveraging additional private, local, State, and Federal investments to fight poverty.

STRUCTURE

Critics of Federal anti-poverty programs emphasize the need for State and local leadership to address poverty, asserting that State and local leaders are best equipped to tackle the challenges facing their communities. CSBG embodies this very principle. CSBG is a block grant administered and managed by States, which distribute funds to a nationwide network of over 1,000 local CSBG Eligible Entities, also known as Community Action Agencies or CAAs. The CSBG network serves every corner of America, touching urban, rural, and suburban communities. In some rural counties, the CAA is the only human services organization working to promote economic security in that community.

Community Action Agencies utilize CSBG funds to address specific needs, which may include services and programs that address one or more of the core domains in which we work: employment, education and cognitive development, income, infrastructure and asset building, housing, health and social behavioral development, and civic engagement and community involvement. The CSBG Act also requires that the work of Community Action Agencies must be shaped by a community needs assessment performed at least every 3 years. This process ensures that CAA programs and services are evidence based and tailored to unique community needs, rather than a one-size-fits-all solution. The needs assessment prevents duplication and incorporates community feedback in the strategic planning process. Furthermore, the CSBG Act requires at least one-third of a Community Action Agency's board to be composed of people with low-incomes or their representatives, ensuring that local needs are accurately reflected in the priorities of the organization.

In addition to low-income representation, the CSBG Act also requires Community Action Boards be comprised of local elected officials or their representatives and community stakeholders which include local businesses, other helping organizations, professional groups, or community organizations. This unique tripartite structure assures that the Community Action Agency not only properly identifies the needs of a community, but also identifies the available resources and opportunities that can be leveraged to maximize outcomes and impact. The tripartite structure of Community Action boards calls on all sectors of society to join in the fight against poverty.

ACCOUNTABILITY

In addition to a structure that empowers States and local communities, CSBG is bolstered by a Performance Management Framework to ensure accountability at all levels of the network. This federally established Performance Management Framework includes State and Federal accountability measures, organizational standards for Community Action Agencies, and a Results Oriented Management and Accountability (ROMA) system. Under the Performance Management Framework, the CSBG Network reports outcomes through the CSBG Annual Report. Within this reporting mechanism, National Performance Indicators are used across the network to track and manage progress, ensuring CAAs have the data they need to improve and innovate. The ROMA system allows local communities to strengthen their impact and achieve robust results through continuous learning, improvement, and innovation. Furthermore, CSBG State Offices monitor local agency performance and adherence to organizational standards, providing training and technical assistance to ensure high quality delivery of programs and services.

IMPACT

CSBG is a sound Federal investment that produces tangible results. Federal CSBG dollars are used to support and strengthen the anti-poverty infrastructure of our communities. In fiscal year 2017, for every $1 of CSBG, CAAs leveraged $7.36 from non-Federal sources. This leveraging of funds allowed CAAs to expand and maintain highly successful programs. Including all Federal sources, non-Federal sources, and volunteer hours valued at the Federal minimum wage, the CSBG Network leveraged $20.22 of non-CSBG dollars per $1 of CSBG. Without CSBG, many rural communities across America would not be able to implement critical programs that address poverty at both the community and family levels. Terminating CSBG would be detrimental to the lives of the over 15.3 million people with low-incomes who the CSBG network served in fiscal year 2017. Here is just a snapshot of the impact of CSBG:

—173,775 unemployed, low-income people obtained a job as a result of Community Action.

—52,220 low-income people with jobs obtained an increase in income and/or benefits.

—38,947 low-income people achieved “living wage” employment and/or benefits.

—425,445 low-income participants obtained healthcare services for themselves or a family member.

—360,909 low-income families in CAA tax preparation programs qualified for a Federal or State tax credit. (The expected total amount of tax credits was $459,277,981).

—134,109 low-income people completed Adult Basic Education (ABE) or General Educational Development (GED) coursework and received a certificate or diploma.

Looking beyond the data, we can see that the CSBG Network is delivering innovative, comprehensive, and effective programs across the country that put individuals and families on a path out of poverty:

—*Economic Self-Sufficiency in Pennsylvania:* Bucks County Opportunity Council (BCOC) is a Community Action Agency that has been running its Economic Self

Sufficiency program since 1997. Using a comprehensive approach, the program addresses the root causes that keep people with low incomes in poverty. BCOC helps participants acquire education, skills, and employment to permanently transition out of poverty. The average annual family income for participants when starting the program was $8,952. By the end of the program, the average family income was $48,280. All Economic Self-Sufficiency graduates have achieved employment that pays a family-sustaining wage, access to safe reliable transportation, affordable housing, a balanced household budget, and a health plan for the entire family. Most notably, graduates of the program no longer receive Federal or State subsidies such as cash assistance, food stamps, and subsidized housing.

—*Preventing Homelessness and Creating Affordable Housing in Oregon:* Oregon is working through its network of 17 Community Action Agencies to make a stable home a reality for more parents, grandparents, children, and veterans. CAA's are critical implementers of the State's Emergency Housing Assistance (EHA) and the State Homeless Assistance Program (SHAP) at the local level. Oregon CAA's are trusted community partners that not only connect members of the community to affordable housing, but also preserve and create units of affordable housing in the community. Stable housing is critical to keeping individuals employed, in school, and on a path to economic security.

—*Collective Impact in Florida:* Pinellas Opportunity Council, Incorporated is the Community Action Agency serving St. Petersburg, Florida. Pinellas is a founding member of the 2020 Plan Task Force, which is a Collective Impact group started in 2015 whose goal is to reduce poverty in St. Petersburg by 30 percent by the year 2020. The 2020 Plan formula for accelerating poverty reduction is threefold: increasing incomes, targeting parents, and strengthening families. Because poverty is defined by income, 2020's major focus is to increase incomes through full-time, part-time, and self-employment. The 2020 initiative targets employment primarily to parents-in-poverty because for every parent who exits poverty, an average 1.4 children do as well. The goal is for 70 percent of parents served (2,450) to remain on track by the 2020 Census. In addition to job training, placement, and retention support, 2020 also uses wrap-around family services to help parents become active in their children's success.

In closing, we ask the committee to fund CSBG at no less than $775 million for fiscal year 2020, the funding level necessary to grow and sustain this nationwide network with an over 50-year record of success. The structure of CSBG empowers States and local communities to take the lead on reducing poverty, while prioritizing locally determined solutions. The CSBG network is subject to the extensive accountability mechanisms of the CSBG Performance Management Framework, ensuring effective and responsible stewardship of funds at the Federal, State, and local level. CSBG is producing concrete results, serving millions of vulnerable Americans each year and implementing strategies that that move communities, individuals, and families toward economic security and independence. NASCSP looks forward to working with Committee members in the future to ensure that CSBG continues to help families achieve outcomes that strengthen our communities and make a difference in the lives of our most vulnerable neighbors. Thank you.

Respectfully.

[This statement was submitted by Jenae Bjelland, Executive Director, National Association for State Community Services Programs.]

PREPARED STATEMENT OF THE NATIONAL ASSOCIATION OF ACCOUNTABLE CARE ORGANIZATIONS

Thank you Chairman Blunt, Ranking Member Murray, and members of the Subcommittee for the opportunity to provide written testimony on behalf of the National Association of Accountable Care Organizations (NAACOS), the largest association of ACOs. Representing more than 5 million beneficiary lives through 330 Medicare Shared Savings Program (MSSP), Next Generation Model, and commercial ACOs, NAACOS requests that the Subcommittee include report language in the fiscal year 2020 LHHS–ED funding bill that would:

—Encourage the Centers for Medicare and Medicaid Services (CMS) to ensure the process for the development of new healthcare delivery and payment models, and modifications to existing models, by the Centers for Medicare and Medicaid Innovation (Innovation Center) is transparent and open for stakeholder comment prior to publication of such models.

Congress established the Innovation Center to test different delivery and payment models to improve quality and reduce costs in Medicare and Medicaid. Today there is no standard process, however, for public input on Innovation Center model development, which can be especially concerning in the case of mandatory models. The Innovation Center often communicates changes through contract amendments, sometimes in the middle of a performance year.

Last month, NAACOS joined 8 healthcare organizations sending a letter to CMS officials highlighting that the Innovation Center's work needs a public process to allow stakeholder comment on all model design elements prior to finalizing the model.[1] Model changes also need to be made and communicated clearly and publicly.

Earlier this year, House Ways and Means Committee leaders Richard Neal (D–MA) and Kevin Brady (R–TX) also called for greater transparency in the Innovation Center's work, saying its model-development process has "historically been opaque to Congress and to stakeholders."[2]

There is a wealth of expertise from those on the front lines of healthcare delivery and payment transformation-knowledge that should be solicited throughout a more public process of developing and updating models. NAACOS appreciates this opportunity to provide the Subcommittee with testimony on ways to improve transparency in the development of value-based payment models. We look forward to working with you.

[This statement was submitted by Clif Gaus, President and Chief Executive Officer, National Association of Accountable Care Organizations.]

PREPARED STATEMENT OF THE NATIONAL ASSOCIATION OF COUNCILS ON DEVELOPMENTAL DISABILITIES

Chairman Blunt, Ranking Member Murray and members of the committee, the National Association of Councils on Developmental Disabilities (NACDD), a national membership organization for the State Councils on Developmental Disabilities (DD Councils), appreciates the opportunity to present this testimony. NACDD respectfully requests that Congress appropriate $80 million for the DD Councils within the Administration for Community Living (ACL) in the Labor-HHS-Education appropriations bill for fiscal year 2020 and clarify in report language that not less than $700,000 of that amount be provided for technical assistance and training for the DD Councils.

Authorized by the bipartisan Developmental Disabilities Assistance and Bill of Rights Act (DD Act), DD Councils work collaboratively with the University Centers for Excellence in Developmental Disabilities (UCEDDs) and Protection and Advocacy program for Developmental Disabilities (P&As), to "assure that individuals with developmental disabilities and their families participate in the design of and have access to needed community services, individualized supports, and other forms of assistance that promote self-determination, independence, productivity, and integration and inclusion in all facets of community life, through culturally competent programs."[1] The DD Act design threads these three distinctly different programs together to ensure a well-trained cadre of experts provide services to individuals with DD and their families, protect the rights of individuals with DD, and ensure that people with DD are fully included in the work to improve services and systems to make them fully inclusive. Working within this Federal framework, the role of the DD Councils is to promote person-centered and family-centered system improvements with and for people with developmental disabilities.

Since 1970, Congress has recognized that DD Councils are in a strategic position in each State and territory to invest in dynamic and innovative programs that improve services and systems that help people with developmental disabilities live in the community. Appointed by Governors, and consisting of at least 60 percent people with DD and their families, DD Councils assess problems or gaps in the system and design solutions. Innovative solutions from the DD Councils often bring about public-private partnerships that make real changes to systems such as transportation, education, healthcare, housing and more.

This fiscal year 2020 funding request reflects the need for DD Councils to direct resources through partnerships with local non-profits, businesses and State and local governments, to overcome obstacles to community living for people with DD. Community living provides supports and services that empower children and adults

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[1] https://www.naacos.com/assets/docs/pdf/2019/CMMI-Letter3.26.19.pdf.

[2] https://waysandmeans.house.gov/sites/democrats.waysandmeans.house.gov/files/documents/Neal-Brady%20letter%20to%20CMS%20re%20CMMI%202019-01-09.pdf.

[1] 42 U.S.C. 15001(b).

with DD to live their lives to the fullest. People with DD are living longer and contributing to the social and economic growth of our country at historic levels. States and territories rely on DD Councils to turn fragmented approaches into innovative and cost-effective strategies to increase the percentage of individuals with DD who become independent, self-sufficient and integrated into the community. DD Council work helps people with DD realize competitive and integrated employment, access to qualified direct support workers, successfully transition to independent living, access affordable housing, build leadership and advocacy skills, and more. DD Council members also provide a critical and unique role in educating State and local policymakers by directly participating in the design of State and local government-funded supports and services affecting their lives.

DD Councils promote community living in the States through narrowly tailored, State specific initiatives. For example, even though persons with developmental disabilities want to go to work and continue to be contributing members to the workforce, national statistics indicate that persons with developmental disabilities experience significantly higher unemployment rates than their peers without disabilities. The Missouri DD Council invests funds towards statewide efforts that contribute to expanding opportunities for persons with developmental disabilities to get and keep competitive jobs in integrated work settings. The DD Council supported a project called Show-Me-Careers, which scaled up evidence-based practices in eight pilot communities. The project adopted a variety of approaches, including skill-building of youth, career planning, and development of partnerships with the local business community. Furthermore, recognizing lack of transportation was a significant obstacle to employment, the DD Council partnered with three Regional Planning Commissions and leveraged funding with the Missouri Department of Transportation (MODOT) to launch MO–RIDES, a referral service that connects riders to transportation providers. MO–RIDES works with existing transportation providers to find affordable, accessible and flexible transportation for people with DD who need a ride to work, appointments or shopping, thus improving their quality of life, by giving them greater access to their community.

Another example of local solutions stemming from DD Council efforts comes from Washington. The popular understanding of Autism spectrum disorder focuses primarily on children and the importance of early detection and intervention. However, Autism is a lifelong condition and supports and treatments change as people grow older. The Washington State DD Council is leading a 5-year Community of Practice to explore different ways of supporting families with individuals with Autism across his or her lifespan. Some of their work includes developing strategies to address the needs of aging caregivers, establishing an adult sibling support network, educating parents with intellectual and developmental disabilities about parenting support services, and more.

The Georgia DD Council is another great example of Councils applying State-based solutions to obstacles to community living. Individuals with disabilities should have the opportunity to live full, self-determined lives in the community. That is why the Georgia Council on DD is the lead supporter of the UNLOCK! Coalition. UNLOCK! works to rebalance the State system of long-term services and supports, so that fewer dollars are spent on institutional care and more dollars are invested into home and community-based supports. Because of UNLOCK!, self-advocates, their families, providers, and other allies successfully advocated to bring additional resources for long term supports and services for people with disabilities to their State.

The 56 DD Councils require continuous support in order meet the requirements of the DD Act. The DD Act provides funding for technical assistance to DD Councils on how to implement the DD Act.[2] Previously funded through Projects of National Significance within the Administration for Community Living, starting in fiscal year 2018, Congress authorized the same technical assistance within the appropriation for DD Councils. Unlike previous years, the fiscal year 2018 and fiscal year 2019 legislation did not contain report language to protect technical assistance funding at levels that reflect the need for these services. Unfortunately, for both fiscal year 2018 and 2019, the Secretary of Health and Human Services reduced funding both through a departmental transfer as well as for other administrative needs in the department. For that reason, NACDD respectfully requests that the committee include report language reflecting minimum levels of funding of not less than $700,000 for technical assistance and training.

Thank you for consideration of this request.

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[2] The Information and Technical Assistance for Councils on Developmental Disabilities is a federally funded technical assistance project authorized by Section 129(b) of PL 106–402.

PREPARED STATEMENT OF THE NATIONAL ASSOCIATION OF COUNTY AND CITY HEALTH OFFICIALS

The National Association of County and City Health Officials (NACCHO) is the voice of the nearly 3,000 local health departments—including city, county, metropolitan, district, and tribal agencies—across the country. As community chief health strategists, local health departments collaborate with community and private-sector partners to ensure the safety of the water we drink, the food we eat, and the air we breathe. They are a critical part of every community's first response to a range of public health events, including disease outbreaks like measles or the opioid epidemic or disasters like hurricanes or acts of terrorism.

However, in recent years, local public health budgets have stagnated or been cut, and recent public health emergencies-like the measles outbreaks, hurricanes, and wildfires- highlight the need to better fund our nation's broader public health infrastructure, including workforce.

Federal funding is critical to this effort, particularly appropriations for the Centers for Disease Control and Prevention (CDC). Through CDC, the Federal Government provides critical funding and technical assistance for local, State, and national programs to strengthen public health capacity, share timely and critical information, and improve health to save lives. Unfortunately, in recent years the CDC's funding has remained static and has not kept pace with inflation. That is why NACCHO is part of a coalition of more than 80 organizations requesting at least a 22 percent increase in CDC funding by 2022. For fiscal year 2020, NACCHO urges the Senate to provide $8.2 billion for CDC, as the House Appropriations Committee did in its bill. With an increased Federal investment in CDC funding, the agency will be better able to implement effective programs to address local, State, and Federal public health priorities. There are also key programs in other Health and Human Services agencies, including in the office of the Assistant Secretary for Preparedness and Response, that are vital to promoting local public health. NACCHO highlights the following key line items that are particularly important to local health departments this year.

PUBLIC HEALTH EMERGENCY PREPAREDNESS COOPERATIVE AGREEMENTS

NACCHO appreciates the increased funding for emergency preparedness provided in fiscal year 2019 and urges the Subcommittee to provide $824 million for the Public Health Emergency Preparedness (PHEP) Cooperative Agreements in fiscal year 2020. Without the support that PHEP provides, local health departments—55 percent of whom rely solely on Federal funding for emergency preparedness—would be without the critical resources necessary to effectively prepare for and respond to public health emergencies such as terrorist threats, infectious disease outbreaks, natural disasters, and other emergencies. In 2018, Congress spent nearly $100 billion to provide relief from hurricanes, devastating wildfires, and other extreme weather events which took 247 lives. (see Washington Post, "Wildfires, hurricanes and other extreme weather cost the Nation 247 lives, nearly $100 billion in damage during 2018." February 6, 2019.) Without the support of PHEP, the cost could have been much higher. A comprehensive, cost saving and proactive public health approach to disaster preparedness helps communities effectively mitigate the damage and costs of disasters and help recover in the aftermath.

HOSPITAL PREPAREDNESS PROGRAM

NACCHO recommends $474 million in fiscal year 2020 for the Hospital Preparedness Program (HPP). HPP funding helps enhance coordination between local public health and the healthcare system to strengthen the ability of hospitals, medical first responders, and medical provider networks to prepare for and respond in the case of an emergency. As the only source of Federal funding that supports regional healthcare system preparedness, HPP promotes a sustained focus to improve patient outcomes, minimize the need for supplemental State and Federal resources during emergencies, and enable rapid recovery. HPP supports over 470 regional healthcare coalitions across the Nation.

MEDICAL RESERVE CORPS

In fiscal year 2020, NACCHO requests $11 million for the Medical Reserve Corps (MRC), a program that enables medical, public health, and other volunteers to address local health and preparedness needs. The program includes nearly 200,000 volunteers enrolled in almost 1,000 units across the Nation, with more than two-thirds of MRC units operated by local health departments. MRC volunteers are an important community asset, filling in gaps and providing key public health services such as immunizations, health education and chronic disease screenings, in addition to quickly mobilizing before, during and after emergency situations. In 2017, MRC provided a $4 million economic benefit during the hurricane response.

IMMUNIZATION PROGRAM

NACCHO requests $711 million for the Immunization Program in fiscal year 2020. The Immunization Program offers local health departments the ability to purchase cost effective and lifesaving vaccinations, conduct widespread outreach initiatives, provide important data collection and surveillance to avert outbreaks, target limited resources, and provide immunization services to at-risk populations. In the midst of the largest measles outbreak in two decades, a strong, coordinated immunization infrastructure is critical to prevent debilitating and life-threatening diseases in both children and adults.

OPIOID ABUSE AND OVERDOSE PREVENTION

More than 47,000 Americans lost their lives due to an opioid overdose in 2017, and the epidemic costs the United States nearly $80 billion per year. NACCHO thanks the committee for increasing opioid funding for CDC by $350 million in fiscal year 2018 and sustaining this level of funding. NACCHO urges the committee to build upon that momentum and provide $650 million in funding for CDC in fiscal year 2020 to bolster surveillance and allow communities to keep building on evidence-based and experience-tested methods of prevention.

In fiscal year 2019, Congress highlighted the need for opioid funding to reach local communities, with specific direction to CDC to allow local health departments to be eligible to apply for these funds. NACCHO urges the Committee to include this language again in fiscal year 2020 to ensure that these funds reach local communities.

In conclusion, robust Federal investment can help us turn the tide and ensure all of our communities have what they need to be safe and healthy. Thank you for your attention to these recommendations to address the Nation's urgent public health challenges.

[This statement was submitted by Lori Tremmel Freeman, MBA, Chief Executive Officer, National Association of County and City Health Officials.]

PREPARED STATEMENT OF THE NATIONAL ASSOCIATION OF DRUG COURT PROFESSIONALS

Chairman Blunt, Ranking Member Murray and distinguished members of the subcommittee, I am honored to have the opportunity to submit my testimony on behalf of this Nation's more than 3,000 drug treatment courts and the 150,000 people they will connect to life-saving addiction and mental health treatment this year. Given the unprecedented success of drug treatment courts and the growing need in communities around the country for solutions to the addiction epidemic, I am requesting the Congress maintain the enacted fiscal year 2019 number of $70 million for the Drug Treatment Court Program at the Department of Health and Human Services, Substance Abuse and Mental Health Services Administration (SAMHSA).

I serve as the associate circuit judge in Stone County, Missouri, where, for much of my 17-year tenure, I have presided over our county's drug treatment courts. I have never come across a more effective approach to promoting public health while protecting public safety. Strong evidence shows it reduces not only crime but also the heavy taxpayer burden wrought by an overcrowded justice system. In fact, I've dedicated much of my professional career to expanding the model as chair of the Missouri Supreme Court Committee for Treatment Courts, president of the Missouri Association of Treatment Court Professionals and a faculty member for the National Drug Court Institute. But, most importantly, at home in Stone County, I preside over our adult drug court, DWI court and veterans treatment court.

Stone County is a rural, relatively quiet part of Southwest Missouri, but we are not immune from the chaos and suffering caused by addiction and related crime. Over the course of my career, I've seen thousands of individuals cycle in and out of our justice system, committing crimes in service to their addiction or mental health disorder. Our drug treatment courts unite public safety and public health to put a stop to that cycle. We hold offenders accountable for their actions and connect them with evidence-based treatment to address the underlying cause of the crime so it doesn't happen again.

I am proud to report that funding from the Substance Abuse and Mental Health Services Administration allows our drug treatment court programs to expand capacity, offering more evidence-based treatment for more people in the justice system in need. Our SAMHSA dollars allow us to partner with Drury University in Springfield, Missouri for ongoing, independent evaluations of our program, giving us the statistics to show our Federal, State and local funding is a positive investment in the future of our community. This work helps us end the generational cycle of addiction we see all too often in Stone County.

Several years ago, I met Kelly, a young mother raising her son in the midst of a severe addiction to methamphetamine. After multiple arrests and a stint in prison, where she was not offered the treatment she desperately needed, Kelly found herself in front of me in the Stone County Adult Drug Court.

In drug treatment court, each participant is assessed and given a treatment plan designed for their unique success—often including medication-assisted treatment as one of the many tools for helping participants find a path to recovery. Kelly received treatment specific to her unique needs.

Treatment, of course, is not enough. Kelly was held accountable by a multi-disciplinary team of law enforcement, probation, defense counsel, prosecution and case management. She frequently appeared before me so I could review her progress, reward her for doing well and encourage her when she faltered. Together, the team provided the ongoing supervision and support expected of our justice system by the community.

Today, Kelly is a productive member of our community. She credits drug treatment court with saving her life. As is often the case, Kelly's addiction negatively impacted her son, Shane. Shane also suffered a severe addiction of to methamphetamine and following an arrest, he too was placed in my drug treatment court. With the help of his mom, now sober, and the accountability of our court, Shane is now living a life in recovery and helping to raise his child—a child that will grow up with a father and grandmother free from addiction and crime. The generational cycle stopped with Shane.

Kelly and Shane are just two examples of the 150,000 people nationally who get access to treatment through drug treatment courts each year. What started as an experiment three decades ago is today the most successful strategy for addressing addiction and mental health in the justice system. In fact, no other intervention in our Nation's history has anywhere near comparable evidence of both reducing recidivism and saving taxpayer dollars.

The Government Accountability Office finds drug treatment courts reduce crime by up to 58 percent. Further, in what is widely regarded as the most comprehensive study on drug treatment courts to date, the Department of Justice, National Institute of Justice Multi-Site Adult Drug Court Evaluation (MADCE) confirmed drug treatment courts significantly reduce both drug use and crime and found cost savings averaging $6,000 for every individual served. The MADCE further found drug treatment courts improve education, employment, housing and financial stability for nearly all participants. They are proven to promote family reunification, reduce foster care placements and increase the rate of addicted mothers delivering babies who are fully drug-free.

But the dollars and cents of drug treatment court is never a substitute for the real successes of people who not only rise above their burden on society but contribute positively to their community. When a young man named Keaton came to my courtroom almost 10 years ago, I could tell he was smart but headed down the wrong path. He had an addiction to opioids and was committing crimes in our community to support it. But after intense treatment and ongoing accountability, Keaton came around. Soon, he was on the path to recovery and, for the first time in a long time, he had his sights set on the future. Keaton went to college, graduating with a degree in nursing. But with a new lease on life, Keaton wanted more—he eventually went back to school and today is a doctor of nurse anesthesia. When that smart young man stood before me, I was focused on saving his life—little did I know he'd be saving lives himself just a few years later.

Our program in Stone County benefits greatly from Federal funding provided by the Department of Health and Human Services. I strongly urge this committee to recommend level funding to the Drug Treatment Court Program so people like Kelly, Shane, Keaton and the 1.5 million others served by drug treatment courts in the last 30 years don't slip through the cracks of our justice system.

[This statement was submitted by Judge Alan Blankenship, Circuit Court of Stone County, Missouri on the Drug Treatment Court program at the Substance Abuse and Mental Health Services Administration, Department of Health and Human Services on behalf of the National Association of Drug Court Professionals.]

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 Older Americans Act Title III(C) senior nutrition program within the Administration for Community Living (ACL) and for the Senior Community Service Employment Program within the Department of Labor. We support funding the Title III(C) nutrition program at $1 billion for fiscal year 2020 and the Senior Community Service Employment Program at $463.8 million for fiscal year 2020, both levels approved by the House Appropriations Committee.

OLDER AMERICANS ACT TITLE III(C) SENIOR NUTRITION PROGRAMS

Older Americans Act (OAA) congregate and home-delivered meals programs are provided in every State and congressional district in this Nation. Approximately 2.4 million seniors in 2017 received these services.

First, thank you for your bipartisan leadership last fall in the passage of the fiscal year 2019 appropriation bill, and for the $10 million funding increase for the III(C) nutrition programs, which built on the much-needed increase provided in fiscal year 2018. We also thank you for rejecting the President's call for the elimination of the Social Services Block Grant (SSBG), which also funds home-delivered meals, and funding it at $1.7 billion.

Unfortunately, these funding increases, though much needed, still do not keep pace with the rising cost of food, inflation, and the growing numbers of older adults. In fact, year over year, the number of older adults receiving meals is shrinking even as the need is growing: the OAA network overall is serving 19 million fewer meals to seniors in need than it was in 2005. We know that 58 percent of participants have indicated that one congregate meal provides one-half or more of their total food for the day, and that a 2015 Government Accountability Office report found that 83 percent of food-insecure seniors and 83 percent of physically-impaired seniors did not receive meals through the OAA, but likely needed them. Additional funding for congregate and home-delivered meals in fiscal year 2020 is critical to help to counteract inflation and provide millions of additional meals when combined with State and local funding. Our fiscal year 2020 request would increase funding for these programs by around $93 million.

Investing additional money in the OAA nutrition programs is fiscally responsible. Access to OAA meals is essential to keeping these older adults out of costly nursing facilities and hospitals. For example, Meals on Wheels clients report fewer falls, which currently cost our Nation $50 billion annually in medical expenses, $28.9 billion billed directly to Medicare. Data from ACL's National Survey of OAA Participants indicates that 61 percent of congregate and 92 percent of home-delivered meal recipients say that the meals enable them to continue living in their homes. Further, on average, a senior can be fed for a year for about $1,300, which is approximately the same as the cost of one day's stay in a hospital or less than the cost of 10 days in a nursing home. The cost savings to Medicare and Medicaid that this creates cannot be over-emphasized.

Another benefit provided by the OAA nutrition programs, as called for in the OAA, is the socialization opportunity that the program provides its recipients. Over the course of the last two and a half years, NANASP with a grant from the Retirement Research Foundation has studied the value of socialization. This has included interviews with more than 250 individual older adults at their lunch tables at congregate meal sites, asking them their main reason for attending the program. Easily more than 90 percent answer socialization, which proves the program is doing what was intended. At a time when we have growing concerns about isolation and loneliness among older adults, the OAA congregate nutrition program stands distinctly as a program that has been proactively addressing this issue. Additional support will offer additional opportunities for more older adults to benefit.

Further, the OAA nutrition programs provide jobs to thousands across the country. The programs itself are also flexible, allowing local communities to tailor their local programs to meet the needs of the seniors they serve. These programs are the epitome of a public-private partnership; local programs work in tandem with State and local governments as well as private philanthropy to provide their services, and the OAA nutrition programs participants contribute to the cost of meals on a voluntary basis. In short, the OAA nutrition programs are the model of successful government, and they have worked for over 45 years.

SENIOR COMMUNITY SERVICE EMPLOYMENT PROGRAM

The Senior Community Service Employment Program (SCSEP), also known as Community Service Employment for Older Americans, is authorized by the Older Americans Act but administered and funded by the Department of Labor. It is the only Federal program that directly helps older workers. We thank you for rejecting the President's call for the elimination of SCSEP in fiscal year 2019.

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, which benefits OAA nutrition programs tremendously.

SCSEP participants provided more than 34.8 million paid staff hours to over 20,000 local public and nonprofit agencies, such as libraries, schools, and senior centers in Program Year (PY) 2015. Further, the value of the community service provided by SCSEP participants (using Independent Sector's estimated value of a volunteer hour) exceeded $840 million in PY 2017, over twice the total SCSEP PY 2017 appropriations of $400 million.

SCSEP received $400 million in fiscal year 2019, a repudiation of the elimination of the program as supported by the President and level-funding as compared to the previous year. However, this is not enough to meet the growing need for SCSEP—both in participants and in wages. Our request would restore SCSEP's funding levels to the authorized levels for fiscal year 2019 under the Older Americans Act.

SCSEP is the only Federal program targeted to serve specifically low-income older adults seeking employment and training assistance; moreover, the Government Accountability Office has previously identified SCSEP as one of only three Federal workforce programs with no overlap or duplication. The average age of a program participant is 62; according to the Department of Labor, 65 percent of all SCSEP participants in PY 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.

As a job-creator and an unduplicated, successful program, SCSEP should receive consideration for increased funding. We need to preserve the only Federal program serving an especially vulnerable population—low-income older adults—and there is no real alternative to SCSEP.

Thank you for your past and future support of these programs.

[This statement was submitted by Mary Beals-Luedtka, Chair, and Robert Blancato, Executive Director, National Association of Nutrition and Aging Services Programs.]

PREPARED STATEMENT OF THE NATIONAL ASSOCIATION OF RSVP DIRECTORS

The National Association of RSVP Directors (NARSVPD) appreciates the opportunity to submit testimony recommending an fiscal year 2020 funding level of $63 million for the RSVP program, administered by the Corporation for National and Community Service (CNCS). This additional $13 million will help bring successful programs to scale, enable more seniors live independently, support veterans and military families, and combat opioid abuse, as well as meet other local needs.

Older Americans are facing higher costs for assisted living and healthcare and are facing greater social isolation. In many parts of the country—especially counties in the rural Midwest—older Americans are "aging in place" because disproportionate shares of young people have moved elsewhere. This leaves seniors dependent on a frayed social safety net and dependent on volunteers for needed services.

Further, according to the Population Reference Bureau, " The aging of the baby boom generation could fuel a 75 percent increase in the number of Americans ages 65 and older requiring nursing home care, to about 2.3 million in 2030 from 1.3 million in 2010. Demand for elder care will also be fueled by a steep rise in the number of Americans living with Alzheimer's disease, which could nearly triple by 2050 to 14 million, from 5 million in 2013." The need for RSVP has never been greater.

RSVP deploys more than 200,000 volunteers in more than 600 programs to support the efforts of thousands of community organizations across the Nation. It provides opportunities for people 55 and over to make a difference in their communities through volunteer service. It offers maximum flexibility and choice to its volunteers by matching the personal interests and skills of volunteers with opportunities to help solve community problems. It offers pre-service orientation, supplemental insurance while volunteers are serving, and training from the agency or organization in which volunteers are placed. RSVP volunteers get no stipend but are eligible for reimbursement for meals and mileage, as long as program budgets allow for it.

RSVP programs identify community needs and continually recruit, train, place, coach and mentor volunteers while they report to CNCS on how programs are meeting their performance goals and other matters.

RSVP is not means tested and recruits volunteers without regard to income. Most serve between 10 and 40 hours a week, but there is no set schedule. RSVP is flexible allowing volunteers improve the lives of their neighbors and friends every day.

For example, some 667 RSVP volunteers in the Scott and Cape Girardeau Counties, Missouri RSVP program served 99 not-for-profit agencies and generated 76,557 hours of community service worth an estimated $1.9 million. RSVP volunteers drive cancer patients to and from their treatment, tutor and mentor youth and adults, serve in juvenile court to meet the needs of abused and neglected children, visit elderly veterans, serve in State parks, and deliver meals to frail and homebound seniors, among many other volunteer activities.

RSVP is cost-effective and an excellent investment. The average Federal RSVP grant is about $78,000. This is less than the $89,300, which was national annual median cost of a semi-private room in a nursing home in 2018. In many States, it costs more to put one senior in a nursing home for a year than it does to support an entire RSVP program. Using Independent Sector's estimate of the value of an hour of volunteer service, RSVP volunteers provide more than $1 billion worth of service to the Nation each year.

RSVP 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 estimated that States and local communities would have contributed $39 million in non-Federal support in fiscal year 2017.

Volunteers improve the quality of life for volunteers and those they help. According to an article published on April 22, 2018 in the Wall Street Journal, a study of 2,705 volunteers age 18 and older from found that 75 percent of those who volunteered in the past 12 months said volunteering made them feel physically healthier. A much larger study-one involving more than 64,000 subjects age 60-suggests that volunteering slows the cognitive decline of aging. The author of that study, Dr. Sumedha Gupta reported, "The effect is significant. It's consistent," Dr. Gupta said. Further, "we find that as people volunteer, their cognitive health scores improve. If they don't volunteer, their cognitive scores decline faster." The reasons behind volunteering's boost to cognitive health, Dr. Gupta said, have to do with the unique characteristics of such activity. Unlike paid work, there is a "different subjective well-being" or "warm glow" that a volunteer experiences from helping people. Volunteering is also unique "because it supplies mental, physical and social stimulation in one package," Dr. Gupta said. "You have to move around, you interact with people, you think about activities."

Further, Baby boomers are particularly susceptible to loneliness, which undermines health and is linked to early mortality, and has been found to shorten lives as much as smoking or drinking. Being lonely may be worse than being obese. A study of recently widowed older adults found that "higher intensity volunteering may be a particularly important pathway for alleviating loneliness among older adults."

RSVP volunteers support students. In Davidson and Williamson Counties, Tennessee, RSVP's signature program is Friends Learning in Pairs (FLIP), an intergenerational volunteer tutoring program that matches adults 55+ with students in Davidson and Williamson County elementary schools for one-on-one academic support in reading or math. Through weekly one-on-one tutoring sessions throughout the school year, RSVP volunteers provide the individual support, encouragement and friendship struggling students need in order to succeed. In the school year 2017/18, 108 FLIP tutors served 422 students in 30 partner schools with the following results: 86 percent of students served either achieved grade level proficiency or increased their academic grade level by at least 1/2 grade, 96 percent of teachers referring a child to FLIP indicated the program helped them achieve their goals for student improvement, and 93 percent of volunteer tutors indicated that they were able to make a positive difference in a child's life as result of volunteering with the FLIP program.

RSVP helps other seniors to live independently. RSVP volunteers help keep seniors 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 and avoid early institutionalization. Fifteen RSVP volunteers assist with local meal deliveries to frail and homebound seniors. Last year, RSVP volunteers made more than 4800 deliveries, ensuring that seniors received a nutritious meal. Volunteers also interacted with these seniors and were able to help them remain in their homes and avoid premature institutionalization.

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, online applications and mock job interviews for veterans and military families, and assisting veterans and military families in researching and locating housing, schools, and support services. All told, last year these RSVP volunteers helped more than 200 veterans and military. The first RSVP Veterans Coffeehouse in Connecticut was established by Thames Valley Council for Community Action's RSVP in Killingly in 2015. More than 433 guests, including 157 veterans, attended the coffeehouse during its first 6 months. The coffeehouse provides socialization for isolated veterans. Through connections made at the coffeehouse, several veterans have been able to gain access to additional services and benefits. Two veterans were awarded full disability for Agent Orange complications. A 92-year-old veteran received two new hearing aids at no charge. Eight veterans began receiving housing, energy, medical and food assistance through the Soldiers, Sailors & Marines Fund. Other veterans are gaining access to healthcare through the Veterans Administration as a result of the coffeehouse.

RSVP is a "destination" for retiring "baby boomers." Some 10,000 "baby boomers" retire everyday and will do so everyday for the next 20 years. RSVP is the only national program able to place large numbers senior volunteers in high quality volunteer positions. CNCS reported that RSVP has increased the number of baby boomers in the program and provides those volunteers with high quality activities that make use of their skills. Baby boomers enrolled in RSVP volunteer over 100 hours more than their counterparts who are not associated with RSVP. Virtually all of RSVP baby boomers who recruit/coordinate other volunteers are likely to continue in the program.

Take the case of Nancy who moved to Seattle in 2017 to be near one of her children. Soon after arriving in the Seattle area, Nancy picked up a free newspaper at the grocery store and read an article on volunteering listing Solid Ground's RSVP program as a place to call for senior volunteer opportunities. After consulting with RSVP, Nancy chose the Chicken Soup Brigade (CSB) program at Lifelong, a community health organization offering a wide variety of services for people living with chronic illnesses. CSB has been serving clients across the greater Seattle area with nutritious food and meals for over 30 years. Every week, staff and over 200 volunteers prepare, package and hand deliver more than 1,000 nutritionally specific meals. The food and meals are processed from CSB's main distribution center in Georgetown, and then delivered to satellite distribution locations around the area for final delivery to clients. Nancy is the Satellite Site Coordinator at the Bellevue distribution center. Every week, she organizes meals for delivery and supports volunteer drivers as they prepare their deliveries. Nancy has "always been interested in getting food to people who need it," and, she says, "the need in Seattle is enormous."

RSVP is helping in the fight against opioid abuse. Fort Wayne RSVP received a grant in 2017 to help combat opioid abuse that can be replicated at scale. The grant covers four mostly rural counties in Indiana: Adams, Wells, Huntington, and Whitley. The main goal is to develop TRIAD partnerships of three constituencies—law enforcement, older adults, and community groups in each county. The purpose of TRIAD is to promote older adult safety and to reduce the fear of crime that older adults often experience. The TRIAD will serve as a vehicle to promote citizen involvement to address opioid abuse in these mostly rural counties. RSVP volunteers are being recruited to serve in TRIAD event planning, distribution of educational material with a focus on opioid abuse, and assisting at Medication Collection events twice a year and at ongoing year round collection sites. Local Sheriffs have identified topics for community education including lack of knowledge of opioids, the use of Narcan, safe storage of medication in homes, and proper disposal of unused or unwanted opioid medications. Informational programs have been held in each county and have addressed safe storage of medication in the home, proper disposal of medication, and working with local law enforcement if questions or problems arise.

RSVP is an important source of disaster prevention and relief. RSVP volunteers have participated in recovery efforts in Alabama, Missouri, Kentucky, South Carolina, Texas, and New York and have recently been deployed in the aftermath of floods in the Midwest.

We believe that restoring funding for RSVP to $63 million will result in significant benefits to both the volunteers and the communities they serve.

[This statement was submitted by Betty M. Ruth, President, National Association of RSVP Directors.]

PREPARED STATEMENT OF THE NATIONAL ASSOCIATION OF STATE HEAD INJURY ADMINISTRATORS

Dear Chairman Blunt and Ranking Member Murray:

On behalf of the National Association of State Head Injury Administrators (NASHIA), thank you for the opportunity to submit testimony regarding the fiscal year 2020 appropriations for programs authorized by the Traumatic Brain Injury (TBI) Program Reauthorization Act of 2018 administered by the U.S. Department of Health and Human Services (HHS) and the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) authorized by the Workforce Innovation and Opportunity Act (WIOA) of 2014, which transferred NIDILRR from the Department of Education to HHS. NASHIA is requesting;

—$19 million for HHS' Administration for Community Living's (ACL) TBI State Partnership Grant Program

—$6 million for the ACL Protection & Advocacy Grant Program;

—An additional funding to expand the ACL's NIDILRR TBI Model Systems from 16 to 18; and

—$5 million additional funding for the Centers for Disease Control and Prevention's National Center for Injury Prevention and Control for a national concussion surveillance system authorized by the TBI program Reauthorization of 2018.

NASHIA also supports funding for CDC's and ACL's older adult falls prevention program ($2.05 million and $5 million) and the injury control research centers ($9 million).

NASHIA thanks the U.S. Congress for reauthorizing the TBI Act programs last December and for the small increase received this current fiscal year for the TBI State Partnership Grant and P&A Grant programs ($1 million combined). The HHS' ACL Federal TBI State Partnership Grant Program is the only program that assists States in addressing the complex needs of individuals with TBI.

Last spring, ACL awarded four-year grants to 24 States at either $300,000 or $150,000 annually to improve and expand service delivery. The AC TBI State Protection & Advocacy (PATBI) grant program awards grants to each State and territory at a minimum of $50,000. The requested amount will increase the amount awarded to State and PATBI grantees, as well as to increase the number of State awards to reflect the expanding number of Americans with a TBI needing public resources.

In 2013, 2.8 million Americans sought treatment for or died from a TBI as the result of a car crash, fall, sporting or recreational injury, an assault or other contributing factor. A TBI may cause problems with cognition, emotions, language, physical mobility and sensory affecting how a person is able to return to school, work, home and community. It is a complex disability that challenges States' ability to provide the right services at the right time.

Over the course of recovery, a combination of private and public entities are involved, including emergency departments; medical and rehabilitative facilities and programs, such as trauma designated hospitals; post-acute rehabilitation programs; education, if school aged; vocational rehabilitation, if returning to work; therapies to maintain physical and cognitive functioning; and community services and supports to enable the individual to return to the community to live as independently as possible. Payers for these type of services include private health insurance, Workers' Compensation; Medicaid; Medicare; State revenue; private pay; and public assistance programs. Navigating this path to recovery is overwhelming for individuals and their families. To assist with the coordination of rehabilitative care, services and supports, many States have developed service coordination or case management systems supported by Medicaid, Sate funding or dedicated funding from fines or fees, referred to as trust fund programs. Not all States, however, have this resource and those States that do, may not have adequate provider networks throughout the State.

We are pleased that ACL is beginning to develop a Federal Interagency Coordinating Plan, as called for by the TBI Act. This is being done in recognition of the need to align TBI resources with other Federal aging and disability programs, such as the Lifespan Respite Care, Aging and Disability Resource Centers, and Assistive Technology, to help States maximize and to coordinate Federal resources. States also benefit from research conducted by the TBI Model Systems funded by NIDILRR, also housed in the ACL, to assist with "best practices" to ensure good outcomes.

States primarily incur the burden of TBI with regard to individuals who need ongoing, crisis or short-term services and supports that are not paid for through private healthcare insurance plans. About half of the States have enacted legislation to establish a trust fund program for such purposes; a few State legislatures appropriate general revenue to fund services; about half of the States have implemented brain injury Medicaid Home and Community-Based Services (HCBS) waiver programs; and some State programs use a combination of these funding sources to support the array of needs. These services include post-acute rehabilitation; personal care; service coordination or case management; assistance with activities of daily living; in-home accommodations and modifications; transportation; and therapies, including behavioral, cognitive, speech-language and physical therapies. With limited State resources to address these needs, many individuals, particularly those with behavioral issues, addiction problems, and poor judgment, will find themselves homeless or in correctional facilities.

Since 2009, all 50 States and the District of Columbia have enacted "return to play" laws to address concussion management in youth athletes. States are now beginning to address "return to learn" issues to identify the academic needs of students after a concussion, regardless of cause. The requested $5 million for the CDC's National Center for Injury Prevention and Control to establish and oversee a national concussion surveillance system will greatly assist States as they target their resources to better meet and understand the needs of individuals who sustain a concussion.

Past and current State grantees have identified and assisted high risk populations, which includes youth and adults with TBI in juvenile justice and criminal justice systems; older adults with fall-related TBIs; returning servicemembers and veterans; and young children in pre-school programs through screening, training, and linking individuals to services. At the end of each grant funding cycle States have found it difficult to continue these activities without financial support. Increased and sustainable funding will help to continue this important work.

In keeping with our mission, NASHIA, a nonprofit organization, works on behalf oft States to promote partnerships and build systems to meet the needs of individuals with TBI with the goal of all States having resources to assist individuals with TBI to return to home, community, work and school after sustaining a brain injury, as well as assistance to family members who generally serve as primary caregivers.

In addition, through the ACL falls prevention program and the National Center for Injury Control and Prevention, Federal funding is needed to help States to address injury prevention, including high risk populations such as older adult falls, and to better determine and address through the ACL TBI State Partnership grants.

Again, thank you for this opportunity and your support to better serve Americans, both civilians and military, with traumatic brain injury. Should you wish additional information, please do not hesitate to contact Rebeccah Wolfkiel, Executive Director, at (execdirector@nashia.org). You may also contact Becky Corby, NASHIA Government Relations, at (rcorby@ridgepolicygroup.com) or Susan L. Vaughn, Director of Public Policy, at (publicpolicy@nashia.org). Thank you for your continued support.

[This statement was submitted by Susan L. Vaughn, Director of Public Policy, National Association of State Head Injury Administrators.]

PREPARED STATEMENT OF THE NATIONAL ASSOCIATION OF STATE LONG-TERM CARE OMBUDSMAN PROGRAMS

Chairman Blunt and Ranking Member Murray, I am pleased to present this testimony on behalf of the nearly 71,000 residents in Washington State's long-term care facilities and in collaboration with the National Association of State Long-Term Care Ombudsman Programs (NASOP). Thank you for your past support of State Long-Term Care Ombudsman Programs (SLTCOPs) and the vulnerable citizens that it serves. I submit this statement and the funding recommendations for the fiscal year 2020 for SLTCOPs administered through the Administration for Community Living, in the Department of Health and Human Services to include:

—$20 million for assisted living ombudsman services under Title VII of the Older Americans Act;

—$35 million for our current core funding under Title VII of the OAA; and

—$5 million under the Elder Justice Act for training and services to address increasing abuse, neglect, and exploitation, including related to staff that are part of the opioid crisis.

Long-term care ombudsmen help older adults and people living with disabilities have a good quality of life, receive quality care, and be treated with dignity. LTC Ombudsmen are paid professionals who recruit, train and oversee teams of local volunteers who want to give back to their communities. The advocacy we provide is the first line of protection for thousands of elders living in licensed long-term care facilities. Last year, volunteers in Washington donated approximately 34,002 hours of their time and skill to resolve complaints made to the program with a success rate of nearly 90 percent. We save the State resources by resolving complaints at the lowest level keeping them out of the expensive regulatory and legal systems. However, like our sister program's across the Nation, we are not able to keep up with consumer needs and growing costs which is of concern giving the aging of the baby boomer generation in the U.S.

In Washington and other States, the number of Assisted Living Facility residents has grown tremendously. By the end of 2019, Washington will have 2,000 additional assisted living facility beds but no expansion in ombudsman services. The growing number of long-term care residents makes it financially and resources to provide the cost saving advocacy services provided by LTC Ombudsman Programs.

To alleviate the effects of diminished budgets and expanding long-term care populations, we respectfully request the following funding to support all SLTCOPs.

First, we request $20,000,000 to support SLTCOP work with residents of assisted living, board and care, and similar community-based long-term care settings. While the mandate to serve residents in assisted living facilities was added to our mission Act, there have been no appropriations for this function. Assisted living and similar businesses have boomed, but SLTCOP funding has not increased to meet the demand and respond to the industry boom.

Washington State has demonstrated leadership by reducing costs in their Medicaid system, while improving consumer choice in community based long-term. Assisted living has proven to be a viable option for those who qualify for more costly nursing home care, but wish to exercise their choice to live in assisted living. Assisted living residents have complex medical needs, very much like the nursing home residents of 20 years ago. Growth in the number of assisted living facilities, in conjunction with complex needs of consumers and diminished funding, threatens our Nation's Long-Term Care Ombudsman Programs. These challenges to State Programs hinder our ability to meet program requirements to provide regular and timely access to all residents wanting long-term care ombudsman services. Current funding levels preclude SLTCOPs from quickly responding to complaints and monitoring facilities. Without our eyes and ears in these buildings, residents are at risk of abuse, neglect, and serious financial exploitation, and any number of violations to their rights.

Our second request is for $35,000.000, which is needed to provide core program funding for the program under Title VII of the Older Americans Act. These funds must be allocated to all fifty States. In addition to improving the quality of life and care for millions of vulnerable long- term care residents, our work saves Medicare and Medicaid funds by avoiding unnecessary costs associated with poor quality care, unnecessary hospitalizations and expensive procedures and treatments. Furthermore, nationally in 2016, nearly 7,331 volunteers served in the SLTCOP. For every one staff ombudsman, six volunteer ombudsmen serve residents. Ombudsman staff and volunteers investigated 199,493 complaints made by 129,559 individuals. Ombudsmen were able to resolve or partially resolve 74 percent—or an ombudsman resolved three out of every four complaints investigated.

In 2018, Washington State had 3,818 long-term care facilities with approximately 71,000 residents. Our State program includes myself, and two other full time staff, which has not changed much since 1989. Thankfully, we have great partnerships with other not-for-profits to operate local ombudsman programs, extending our reach into the most isolated of nursing home residents in our rural communities. These partners include seven Area Agency on Aging entities and three Community Action Programs and in total, we employ 17.51 full-time staff. Two national studies about the effectiveness about the LTC Ombudsman Program (the Institute of Medicine, and the Bader Report) have recommended that best practice be to employee one full-time paid staff ombudsman for every 2,000 long-term care residents or licensed beds. Washington State falls short of that goal at having only 49 percent of the needed paid staff.

Although we have a great team of paid and volunteer ombudsmen, our program is still not able to cover every facility in our State. Nearly half of the licensed facilities in our State never receive routine visits by an ombudsman, which is the hallmark activity of the Program and vital to building trusting and effective working relationships. We are so busy responding to complaints and phone calls that we are not able to conduct regular outreach, build presence in all facilities, and make our services known to isolated residents and their family members. We are overwhelmed with complaints about unwanted and unlawful discharges, also known as, "resident dumping" by residents, their loved ones and by hospitals, which involves expensive legal issues, interactions with multiple health and long-term care community systems, State entities and the courts.

Third, we request $5,000,000 to support the work of SLTCOPs under the Elder Justice Act (EJC). This appropriation would allow States to hire and train staff and recruit more volunteers to prevent abuse, neglect, and exploitation of residents and investigate complaints. However, the funds have been authorized since 2010, to date no EJC funds have been appropriated for SLTCOPs. Currently, Federal Older Americans Act funding comprises about a third of the total funding required to maintain the Washington Long-Term Care Ombudsman Program, at its current level, with the majority of funding coming from our State General Funds. We understand that this subcommittee faces a strained financial situation, but a continued commitment to SLTCOPs protects the health and safety of millions of older adults living in nursing homes and assisted living facilities. I believe their protection should remain a high priority.

Demand for our services is growing. The number of complex and very troubling cases that long-term care ombudsmen investigate has been steadily increasing. In addition, there continues to be a disturbing increase in the frequency and severity of citations for egregious regulatory violations by long-term care providers that put residents in immediate jeopardy of harm, which, unfortunately, is true for nursing homes in my State. Ombudsmen are needed now more than ever in nursing homes, assisted living, and similar care facilities where we are required to serve.

The people who operate long-term care facilities have recognized the value and benefit of having ombudsmen assist with staff training and consultation. In order to improve advocacy and services available to residents, our office and NASOP respectfully request the aforementioned funding levels. We also appreciate that the testimony of the Elder Justice Coalition also calls for these increases.

Thank you for your ongoing support.

[This statement was submitted by Patricia Hunter, Washington State Long-Term Care Ombudsman Member, National Association of State Long-Term Care Ombudsman Programs.]

PREPARED STATEMENT OF THE NATIONAL COALITION OF STD DIRECTORS

Chairman Blunt, Ranking Member Murray, and Subcommittee Members:

I am providing this testimony on behalf of the National Coalition of STD Directors (NCSD), a national membership organization representing STD programs at health departments in all 50 States, seven large cities, and eight U.S. territories. This testimony reflects the voices and perspectives of STD programs across the U.S. who are overwhelmed, underfunded and fighting a losing battle against sexually transmitted diseases (STDs).

I have a very simple message for you and that is that the STD prevention program at CDC has been level funded for the last 15 years, and this must change. The result of years of flat funding is historic, out of control epidemics for all reported STDs. If this flat funding continues, these infectious diseases will continue spread at astonishing rates, effecting the health of millions of Americans, including over 1,000 children born with congenital syphilis. Fortunately, the House of Representatives has chosen to act and we ask that the Senate do the same and increase the 2020 funding for STD prevention by $10 million and to take the additional step of providing $5 million for an initiative to end congenital syphilis.

STDs are at epidemic levels and continuing to rise. Data from the Centers for Disease Control and Prevention (CDC) tells us that between 2013 and 2017 syphilis cases increased 80 percent, gonorrhea cases increased 67 percent, and chlamydia cases increased 22 percent. Preliminary 2018 data from Florida, Mississippi, Missouri, Rhode Island, Tennessee, Washington State, and South Carolina show that STD rates continue to increase and will set a record for the fifth year in a row. These epidemics are creating a public health emergency with devastating health consequences including infertility, cancer, transmission of HIV, and infant and newborn death in every corner of our Nation. Supporting the first increase for STD prevention in over 15 years will be an important first step in demonstrating your concern about the growing epidemic, and the health of your constituents and the country as a whole.

Do you know that last year over 1,000 infants were born with congenital syphilis in the United States? Congenital syphilis (CS) is completely preventable— it occurs when syphilis is passed from a mother to her baby during pregnancy or delivery; reported cases have more than doubled between 2013 and 2017 from 361 cases to 918—the highest number of recorded cases in 20 years—in 2018 there will be more than 1,000 congenital syphilis cases. These cases are heartbreaking— up to 40 percent of children born with congenital syphilis will die and the vast majority of these cases are preventable. Are you aware that in 2017 congenital syphilis cases surpassed the number of perinatal HIV cases? This is largely thanks to the Federal investment in innovative approaches, the number of reported perinatal HIV cases has decreased; with your support we can see similar results for congenital syphilis. The Senate must invest $5 million in direct service funding for congenital syphilis prevention and treatment.

The Nation's drug crisis is also having a direct effect on increasing STD rates. On February 14, 2019 a new study from CDC shows that over the last 5 years, methamphetamine, heroin, and other injection drug use more than doubled among heterosexuals with syphilis. STD programs at State and city health departments are ill-equipped to prevent and treat STDs with the added burden of addressing substance abuse disorders. One of our members who oversees a STD program has said the following about this crisis: "STD clinics are essential safety net services for people who otherwise wouldn't have access to healthcare. The people who come to our STD clinics are often affected by the opioid epidemic and the services we provide are essential to keeping these individuals and their communities healthy." If you care about dealing with the infectious disease consequences, then include support for STD services in your response to the opioid epidemic.

If you hope to end the HIV epidemic in this country, then follow the example of the House of Representatives and instruct CDC to include funding for STD programs as important partners in ending the HIV epidemic. These additional funds should be used to: increase HIV testing and linkage to care and for PrEP services at STD clinics; increase Disease Intervention Specialists—boots on the ground experts in community work to prevent STDs and HIV by linking people to care, investigating outbreaks, and providing partner services; increase condom availability and improve data sharing across STD and HIV programs.

In summary, the Federal STD program at CDC has been level funded for 15 years and as a result we have STD rates at epidemic, historic levels and climbing. Level funding means crumbling infrastructure and inadequate tools for preventing new cases of STDs. In order to bend the curve on rising STD rates the Senate must:

—Increase STD funding by $10 million in fiscal year 2020
—Invest $5 million in ending Congenital Syphilis
—Include support for STD programs in response to both the opioid and HIV epidemics.

By taking these small steps, the Senate will show its support for this crucial public health program, and avert STD consequences including infertility, newborn death, new HIV cases, and cancer.

If you have any questions or would like additional information, please contact NCSD's Taryn Couture, Associate Director of Government Relations, at tcouture@ncsddc.org.

Sincerely.

[This statement was submitted by David Harvey, Executive Director, National Coalition of STD Directors.]

PREPARED STATEMENT OF THE NATIONAL COLLEGE ACCESS NETWORK

Dear Chairman Blunt and Ranking Member Murray,

Thank you for your continued leadership over the past two funding cycles to reinforce investments in the programs that support students from low-income backgrounds in their pursuit of higher education. Today, we write first to respectfully request first that the caps be increased for non-defense discretionary funding to prevent unnecessary and automatic cuts to these important programs. This would allow for the continued strong support of the Nation's higher education system and students. And second, NCAN recommends these specific funding levels for the U.S. Department of Education programs:

—A maximum Pell Grant of $6,753.
—Supplementary Educational Opportunity Grant funding of $1.028 billion.
—Federal Work-Study funding of $1.434 billion.
—TRIO program funding of $1.12 billion.
—GEAR UP funding of $395 million.
—MSIs funding to sustain losses due to the expiration of mandatory funding.

Additionally, we would request Corporation for National and Community Service—specifically its AmeriCorps program that allows some college access programs to provide near-peer mentors for their students—receive, at minimum, level funding.

The National College Access Network, founded in 1995, represents more than 450 members across the country that all work toward NCAN's mission to build, strengthen, and empower communities committed to college access and success so that all students, especially those underrepresented in postsecondary education, can achieve their educational dreams. NCAN's members span a broad range of the education, nonprofit, government, and civic sectors, including national and community-based nonprofit organizations, federally funded TRIO and GEAR UP programs, school districts, colleges and universities, foundations, and corporations. All are dedicated to helping underrepresented students access, afford, and succeed in higher education. The Federal investments that would most bolster this goal include the following:

PELL GRANT INVESTMENTS

The Pell Grant award is the cornerstone of financial aid for low-income students. Without this need-based grant funding, an even smaller portion of low-income students would be able to access higher education. Congress recognized the importance of the Pell Grant over the past 2 years by investing in increases in the maximum award of $175 and $100, respectively. Given that the previously required automatic inflationary increases have expired, these annual investments by Congress and crucial to preventing the Nation's students who do not have the means to pay for college from falling farther behind in their pursuit of higher education. Even with these investments, the purchasing power of the Pell Grant for a four-year college degree from a public institution is still holding at a historic low of 28 percent of the cost of attendance.

Due to this loss of purchasing power, NCAN asks for consideration of a bold, multiyear proposal to address the long-term purchasing power of the Pell Grant. At its peak in 1975–76, the maximum Pell Grant award covered nearly four-fifths of a public four-year college education. NCAN realizes the fiscal challenges that face Congress and therefore recommends a multi-year interim step that would return Pell's purchasing power to 50 percent of the cost of a four-year public higher education, or approximately doubling the Pell Grant over the next decade. In order to reach that goal NCAN recommends increasing the maximum Pell Grant 9 percent a year, each year, over the next decade. This plan would result in fiscal year 2020 appropriations including a maximum Pell Grant of $6,753.

If Congress had continued to adjust the maximum Pell Grant award for inflation from 1975, it would be $6,655, only $98 less than requested above. At minimum, Congress should increase the maximum by $150, to $6,345, to match the inflationary adjustment that would have taken place had the automatic adjustments continued.

CAMPUS-BASED AID

As low-income students are piecing together the resources to support their postsecondary pursuits, every dollar and every type of aid counts. For most low-income students, the Supplemental Educational Opportunity Grant (SEOG) and Federal Work-Study help to fill holes in their financial aid packages.

—The average SEOG award for dependent students was $800 for the 2016–17 award year. For the 2018 fiscal year, Congress generously increased the SEOG budget by 14.6 percent, bringing it to $840 million and then held that funding steady for fiscal year 2019. Providing an increase again for fiscal year 2020 will allow institutions of higher education to support a greater percentage of the country's lowest-income students. For fiscal year 2020, NCAN respectfully requests that Congress fund the SEOG program at a total of $1.028 billion.

—Sixty-four percent of today's students work while enrolled in school. The Federal Work-Study (FWS) program allows students to work in a flexible environment, learn important skills, and minimize the amount of time they spend commuting between work and campus. For fiscal year 2020, NCAN respectfully requests that Congress increase the FWS program budget for a total of $1.434 billion.

FEDERALLY FUNDED COLLEGE ACCESS PROGRAMS—TRIO AND GEAR UP

With approximately 1.8 million high school seniors defined as low-income annually, many programs are needed to meet all of their needs as they pursue their options after high school graduation. The NCAN community serves approximately 2 million students annually from middle school through college graduation. To reach all of the students needing services nationwide, our members build important partnerships both with TRIO and GEAR UP programs. NCAN respectfully requests that Congress continue its investment in federally funded college access programs at the amounts requested by their communities: $1.12 billion for TRIO and $395 million for GEAR UP.

MINORITY SERVING INSTITUTIONS

The Higher Education Act (HEA) provides targeted funding to historically black colleges and universities, Hispanic serving institutions, and other minority serving institutions. These institutions serve the students of color, who are disproportionately low-income, at the core of NCAN's mission. Given the delay in reauthorizing, the appropriations process serves as a short-term mechanism to ensure that these programs that support the institutions supporting our students do not receive a drastic fall in their resources. NCAN respectfully requests that discretionary appropriations are increased to sustain all programs receiving mandatory appropriations provided for in HEA Sec 391 until the Higher Education Act can be renewed.

CORPORATION FOR NATIONAL AND COMMUNITY SERVICE

For every dollar spent on national service, the country sees a return on investment that is almost fourfold. Service also plays an important role in the college access movement. In particular, many of NCAN's largest members are able to maximize their impact on underrepresented students by participating in the AmeriCorps public-private partnership. Continuing support for CNCS, and in particular the AmeriCorps program, will enable additional volunteers to work with low-income students, students of color, and students who are first in their family to attend college. NCAN respectfully requests of that the Corporation for National and Community Service and the AmeriCorps program receive at minimum level funding.

Thank you for this opportunity to provide our funding priorities for the fiscal year 2020. A low-income student is about half as likely to complete a postsecondary degree or credential as a high-income student. Through continued supports—both financial and programmatic—our country can work together to close this attainment gap. Thank you again for your support of this important goal.

Sincerely.

[This statement was submitted by Kim Cook, Executive Director, National College Access Network.]

PREPARED STATEMENT OF THE NATIONAL CONGRESS OF AMERICAN INDIANS

The National Congress of American Indians (NCAI) is the oldest, largest, and most representative national organization serving the interests of tribal governments and communities. For 75 years, tribal governments have come together as a representative congress through NCAI to consider issues of critical importance to tribal governments and formulate consensus policy positions. NCAI appreciates the chance to provide the following testimony on funding for tribal and related programs that serve Native people.

U.S. DEPARTMENT OF EDUCATION

Access to quality education is vital for competing and thriving in today's economy. It is an essential strategy for creating jobs and securing the Nation's future prosperity—particularly in tribal communities. An educated citizenry serves as a catalyst to boost tribal economic productivity and growth through a more highly-skilled workforce, which can attract new businesses, reduce unemployment, stimulate reservation economies through direct spending, and foster growth in small businesses owned by tribal citizens as a path to individual and familial self-sufficiency. Accordingly, NCAI requests the following levels of programmatic support.

U.S. DEPARTMENT OF EDUCATION FISCAL YEAR 2020 REQUESTS

Department Education Programs	NCAI Fiscal Year 2020 Request
Title 1, Part A (Local Education Agency Grants)	$20,000,000,000
State-Tribal Education Partnership (STEP) Program	$5,000,000
Title VII funding, ESEA (Impact Aid Funding)	$2,000,000,000
Title VI funding, Every Student Succeeds Act (ESSA)	$198,000,000
Native Hawaiian Student Education (Title VI, Part B)	$40,000,000
Alaska Native Education Equity Assistance Program (Title VI, Part C)	$40,000,000
Indian Education Language Immersion Grants (Title VI, Part D)	$5,000,000
Special Programs for Native Student, Including Native Youth Community Projects	$67,900,000
Title III–A Grants under the Higher Education Act for Tribal Colleges and Universities	$65,000,000
Tribal Colleges and Universities: Adult/Basic Education	$8,000,000
Tribally Controlled Post-Secondary Career and Technical Institutions and Technical Institutions	$10,000,000
Native American-Serving, Non-Tribal Institutions (Higher Education Act, Title III–F)	$10,000,000
Tribal Education Departments (Dept. of Ed)	$10,000,000

Indian Education: Alaska Native Education Program (Title VI, Part C) and Native Hawaiian Education Program (Title VI, Part B): NCAI is concerned that the President's fiscal year 2020 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 that address the unique educational needs of Alaska Native students, as well as the development and operation of student enrichment programs in science and mathematics. The Native Hawaiian Education Program empowers innovative, culturally appropriate programs to enhance the quality of education for Native Hawaiians. It is important to emphasize neither of these programs are duplicative of other programs. NCAI recommends funding the Alaska Native Education Assistance Program at $40 million and the Native Hawaiian Education Program at $40 million for fiscal year 2020.

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

The Federal promise to provide Indian health services was received in good faith by our ancestral tribal leaders to lay the foundation for peaceful co-existence of our great nations. By tribal nations ceding much of their lands, the United States was able to prosper and build great wealth, leaving First Americans to try to build a life within this new nation. The Federal responsibility for providing healthcare to Native people was prepaid by tribal nations. The United States assumed this responsibility through a series of treaties with tribal nations, exchanging compensation and benefits for tribal lands and peace. NCAI requests the following levels of programmatic support in furtherance of the Federal treaty and trust responsibilities.

DEPARTMENT OF HEALTH AND HUMAN SERVICES FISCAL YEAR 2020 REQUESTS

Department of Health and Human Services Programs	NCAI Fiscal Year 2020 Request
Total Fiscal Year 2020 Indian Health Service Funding	$7,030,369,000
Services	$5,242,487,000
Contract Support Costs	$900,000,000
Facilities	$887,883,000
Special Diabetes Program for Indians (SDPI)	$200,000,000
On the TRAIL (Together Raising Awareness for Indian Life) to Diabetes Prevention Program	$1,000,000
HRSA Native Hawaiian Healthcare Systems Program	$19,000,000
Ending HIV Epidemic/Hepatitis C Initiative	$25,000,000
Head Start	$10,810,000,000
TCU Head Start Partnership Program	$8,000,000

DEPARTMENT OF HEALTH AND HUMAN SERVICES FISCAL YEAR 2020 REQUESTS—Continued

Department of Health and Human Services Programs	NCAI Fiscal Year 2020 Request
Native Languages Preservation (NLP), with Esther Martinez Program (EMP)	$14,000,000 for NLP, W/$5,000,000 for EMP
Promoting Safe and Stable Families, Title IV–B, Subpart 2 Discretionary Funds (3 percent tribal allocation reserved from this amount)	$100,000,000
Tribal Court Improvement Grant Program (authorized under Title IV–B, Subpart 2)	$3,000,000
Child Abuse Discretionary Activities, Innovative Evidence-Based Community Prevention Program	$38,000,000
Community-Based Child Abuse Prevention	$50,000,000
Maternal Infant and Early Childhood Home Visiting Program	$420,000,000
Child Welfare Services, Title IV–B, Subpart 1 (tribal allocation reserved from this amount)	$280,000,000
SAMHSA Programs of Regional and National Significance, Child and Family Programs	$8,000,0000
SAMHSA Garrett Lee Smith Grants, State/Tribal Youth Suicide Prevention and Early Intervention Grant	$40,000,000
SAMHSA Garrett Lee Smith Grants, Campus Suicide Prevention Program	$9,000,000
SAMHSA American Indian and Alaska Native Suicide Prevention	$5,000,000
SAMHSA Tribal Behavioral Health Programs (Mental Health and Substance Abuse Programs)	$50,000,000
Older Americans Act (Title VI-Part A,B)	$36,000,000
Older Americans Act (Title VI-Part C)	$10,600,000
Older Americans Act (Title VII-Subtitle B) 1 percent tribal set-aside Low Income Home Energy Assistance Program (LIHEAP)	$4,700,000,000 with $51,000,000 allocated to tribes and tribal organizations

Substance Abuse Mental Health Services Administration: These funds are critical to supporting mental health services and substance abuse prevention activities aimed at high-risk American Indian and Alaska Native youth and their families. NCAI requests $50 million in total for SAMHSA Tribal Behavioral Health Programs ($25 million for Mental Health and $25 million for Substance Abuse Programs).

Head Start: Head Start funds provide early education to more than 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 requests $10.81 billion in total funding for Head Start, which includes Indian Head Start. Additionally, NCAI requests $8,000,000 to fund the Tribal Colleges and Universities (TCUs) Head Start Partnership Program.

Low-Income Home Energy Assistance Program (LIHEAP): NCAI requests $4.7 billion for LIHEAP, with $51 million directly 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.

U.S. DEPARTMENT OF LABOR

Honoring the Federal Government's trust responsibility by addressing key economic needs will help expand tribal economies through increased business and workforce development opportunities. The following fiscal year 2020 budget requests set forth appropriation levels that are essential to empowering self-determined tribal efforts to seed economic prosperity and advance the economic security of tribal nations.

DEPARTMENT OF LABOR FISCAL YEAR 2020 REQUESTS

Department of Labor Programs	NCAI Fiscal Year 2020 Request
YouthBuild Program	$89,000,000
Division of Indian and Native American Programs (DINAP)	$60,500,000
Native American Employment and Training Council	$125,000
Older Americans Act (Title V), Senior Community Service Employment Program	$434,371,000

Senior Community Service Employment Program (SCSEP): NCAI urges Congress to fund SCSEP at $434 million. This program is the only Federal job training program focused exclusively on helping older Americans return to the workforce. Through the program, low-income job-seekers (55 years of age or older) update their skills and contribute to their communities through paid, on-the-job training at schools, hospitals, senior centers, tribal facilities, and other non-profit or public facilities.

CORPORATION FOR PUBLIC BROADCASTING

The ability to communicate keeps communities safe and promotes trade and commerce. Tribal access to modern communications networks supports economic development, tribal governance, healthcare, education, and public safety in tribal and surrounding communities. NCAI requests the following levels of programmatic support.

CORPORATION FOR PUBLIC BROADCASTING FISCAL YEAR 2020 REQUESTS

Corporation for Public Broadcasting	NCAI Fiscal Year 2020 Request
American Indian and Alaska Native Radio Station Grants	$5,000,000
Native Public Media	$500,000
Native Public Media and Koahnic Broadcast Corporation	$500,000

CONCLUSION

NCAI appreciates the opportunity to share these recommendations. Please contact Government Affairs Director Jacob Schellinger (jschellinger@ncai.org) or Policy Analyst Nick Courtney (ncourtney@ncai.org) if you have any questions.

PREPARED STATEMENT OF THE NATIONAL COUNCIL FOR DIVERSITY IN THE HEALTH PROFESSIONS

Chairman Blunt, Ranking Member Murray, and distinguished members of the subcommittee, thank you for the opportunity to submit this statement for the record on behalf of the National Council for Diversity in the Health Professions (NCDHP). I am Dr. Wanda Lipscomb, and I serve as President of the NCDHP and Director of the Center of Excellence for Culture Diversity in Medical Education at Michigan State University. NCDHP was established in 2006 and is composed of institutions that are either currently or formerly distinguished as a "Center of Excellence" through the Health Resources and Services Administration's (HRSA)'s Centers of Excellence (COE) program or are a current or former recipient of the Health Careers Opportunities Program (HCOP) grant, now known as the National HCOP Academies program. Every member institution within the council is committed to advancing pipeline programs and programmatic activity that leads to diversity in the health professions. I am proud to put forth the following recommendations for the fiscal year 2020 appropriations process:

- —$8.56 billion for the Health Resources and Services Administration (HRSA)
  - —$45.21 million for HRSA's: Centers of Excellence (COE)
  - —$47.95 million for HRSA's: National HCOP Academies
  - —$1.75 million for HRSA's: Faculty Loan Repayment
  - —$63.39 million for HRSA's: Scholarships for Disadvantaged Students.

NCDHP is recommending funding levels for COEs and HCOPs comparable to the levels appropriated 15 years ago in fiscal year 2005, adjusted for inflation.

NCDHP is dedicated to promoting the education and training of a workforce that is prepared to provide quality and culturally responsive healthcare to the diverse U.S. population. NCDHP members across the nation are actively involved in health professions education and training, the development of educational pipeline programs for individuals from disadvantaged backgrounds, and the delivery of healthcare to the underserved. Through HRSAs Title VII workforce diversity programs, addressing the long-term healthcare and health professional needs of minority and underserved communities is obtainable. Pipeline program interventions exert a meaningful and positive effect on student outcomes in the health professions. When institutions are strengthened through programs like the COE program, the national capacity to produce a healthcare workforce whose racial and ethnic diversity is representative of the U.S. population is greatly enhanced. The COE program provides grants to health professions schools and other public and nonprofit health or educational entities to increase the supply and competence of underrepresented minority practitioners in the health professions workforce. Programs like the National HCOP Academies or HCOP increase the diversity of the non-nursing health professions workforce by providing grants that improve the recruitment opportunities into the health professions and enhance the academic preparation of students from economically and educationally disadvantaged backgrounds. This program supports students from high school through the completion of their health professions degree. In many instances, it even offers opportunities, such as summer enrichment programs, to ensure the retention and interest of students recruited. Furthermore, The Title VII workforce diversity programs allow institutions to adhere to the best practices in increasing diversity in the health professions as well. These programs allow for institutions to further target and recruit disadvantaged students and offer holistic and comprehensive experiences to their students, institutions to recruit and retain invested faculty to work in underserved communities and underrepresented students, and students to have the financial means of funding their educational experiences.

As you begin the fiscal year 2020 process, NCDHP asks that you further prioritize Title VII health professions training programs. Chairman Blunt, Ranking Member Murray, please allow me to express my appreciation to you and the members of this subcommittee. With your continued help and support, NCDHP member institutions are keeping course to overcome health workforce and health disparities. Thank you for your time and consideration of these requests. We look forward to working with the Subcommittee to prioritize the health professions programs in fiscal year 2020 and the future.

[This statement was submitted by Wanda Lipscomb, PH.D., President, National Council for Diversity in the Health Professions.]

PREPARED STATEMENT OF THE NATIONAL COUNCIL OF 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 2020 Appropriation. NCSSMA respectfully requests that Congress provide at least $13.511 billion in fiscal year 2020 for SSA's Limitation on Administrative Expenses (LAE) account. This level of funding will help ensure the agency can continue to build on the improvements currently underway.

SSA RESOURCES AND KEY FIELD OFFICE AND TELESERVICE CENTER WORKLOAD SERVICE DELIVERY PERFORMANCE

	Fiscal Year			
	2016	2017	2018	2019
SSA's Enacted LAE Funding ($ in Millions)	$12,162	$12,482	$12,869	$12,871
Field Office and Teleservice Center Staff[1]	32,859	31,669	31,913	31,591[2]
Visitors	43,493,551	42,048,301	42,614,871	43,000,000[3]
Left Without Service	2,085,444	1,971,663	2,014,651	2,000,000[3]
Wait Time Without Appointment (Minutes)	28.2	26.5	26.5	28.8[2]
Wait Without Appointment Over 60 Minutes	12.5%	11.0%	10.1%	13.0%[2]
Calls Answered	20,715,568	20,140,219	19,264,131	20,000,000[3]
Calls Unanswered	5,090,701	5,094,339	4,513,100	4,500,000[3]
Phone Answer Rate	80.3%	79.8%	81.0%	81.0%[3]
SSI Redeterminations	2,530,446	2,590,070	2,913,451	2,822,000[4]
Medical CDRs	833,145[5]	854,621[5]	888,670[5]	703,000[4]
Work CDRs	279,945	313,546	314,396	315,000[3]

[1] Full-time permanent staffing in field offices and teleservice centers.
[2] Figure through March 29, 2019.
[3] NCSSMA estimated for fiscal year 2019.
[4] Figure from SSA's Fiscal Year 2019 Congressional Justification.
[5] DDS Performance Report for TII and TXVI CDR Dispositions.

We recognize the current fiscal constraints facing legislators, but we request that Congress provide fiscal year 2020 funding for SSA that is sufficient to improve service to the public while addressing stewardship responsibilities and making much-needed IT infrastructure and systems upgrades. We believe that a $640 million increase over fiscal year 2019 would be a significant step in the right direction, and is needed in order to continue addressing disability backlogs in the hearing offices, initial claims and post-entitlement backlogs in the Program Service Centers and significantly reduced staffing levels in both field offices and teleservice centers. In addition, the Acting Commissioner of Social Security expressed similar resource needs in fiscal year 2020:

> "... The Commissioner's budget includes $13,484 million for total administrative discretionary resources in 2020. This represents $13,270 million for SSA administrative expenses, $106 million in research, and $108 million for the Office of the Inspector General."

We very much appreciate that the House Appropriations Committee recognized the need for increased funding for fiscal year 2020 to help address public service at SSA's field offices and teleservice centers, and included the following Report language earlier this year:

> The Committee includes an increase of $300,000,000 for additional hires and resources to improve public service at SSA field offices and direct service operations, with $22,000,000 specifically for hiring at teleservice center operations. The Committee remains concerned about the excessive waiting times, benefit delays, and service problems faced every day by Americans who are trying to access their earned benefits. It is the Committee's expectation that this funding will be sufficient to replace all losses in the field offices, teleservice and processing centers, and build additional capacity so that offices can function at appropriate levels.

COMMUNITY-BASED SERVICE

The statements below demonstrate how sufficient resources for SSA have a positive impact on the agency's ability to deliver vital services to the American public and in fulfilling the agency's stewardship responsibilities.

> A client had a hearing pending and was in critical condition in the ICU. The field office worked with the representative and hearing office to expedite the case. The Administrative Law Judge (ALJ) agreed to expedite only considering his current condition (progressive stage IV throat cancer). The field office continued to advise on the various outcomes regarding an amended onset and to obtain the documents needed so the judge could make an "on the record" decision. In the end, the client received a quick hearing decision thanks to everyone working together.—*Florence, Alabama*
>
> A homeless individual came into the local field office, accompanied by a friend he had just started living with. He was advised to go to SSA to file a claim for disability benefits. He had just returned to Missouri from another State. Upon review of his record, we found the individual had already filed a claim for disability benefits, had been approved 3 years prior, and had been put into suspense because his whereabouts were unknown. The local office assisted him in getting his benefit reinstated, and because his underpayment was a large sum of money, the SSA technician counseled him on proper use of the underpayment. As a result, he was able to purchase a home in a small town in Kansas, and have funds left over to live on.—*Chillicothe, Missouri*
>
> Our office serves a local State agency that cares for individuals diagnosed with profound mental impairments, such as Down Syndrome. During a recent audit, we conducted a 'meet and greet' with the point person at this agency. We streamlined the communication between our office enhancing service to this vulnerable population. Additionally, we found several missed disabled child benefits entitlements. It appeared as the individuals began to age, information about their parents was never reported to SSA.—*Conway, Arkansas*
>
> A Waterbury man, who was an end stage renal patient, was at risk of losing his new kidney when his Medicare benefits terminated; leaving him unable to afford his kidney transplant medications. The man had lapsed in paying his Medicare premiums, but recently made his payments current. He had been waiting patiently for Social Security's PSC to reinstate his Medicare, but time was running out and he was running out of medication. He contacted the office and management researched the premium problem and brought the issue to the attention of the PSC. The PSC and field office worked together to ensure that his case would get priority attention so that he would not be in jeopardy of losing his new kidney.—*Waterbury, Connecticut*

When SSA's administrative resource needs are unmet, it results in deterioration in key service areas and stewardship workloads. Over fiscal year 2016, the agency saw an increase of about 2 million visitors from the previous year. We expect those numbers to remain relatively constant through fiscal year 2019. Almost 4 million actions are currently pending in the agency's Program Service Centers. These actions are not just numbers, they are actual people, waiting to receive assistance from SSA. Beginning this fiscal year through March 2019, there has been a deterioration in SSA's 800 number service, with a 29-minute wait. This is a 5-minute increase over fiscal year 2018. Over the past two fiscal years, pending hearings have fallen below the one million mark. At the close of fiscal year 2018, there were over 858,000 people waiting for a hearing decision, with an average processing time of 595 days. Sadly, in fiscal year 2017 over 10,000 individuals died while waiting for a decision on their disability application, an increase of more than 1,300 deaths from the prior year. If SSA's administrative funding is not sufficient, we will not be able to continue reducing these backlogs, and public service levels will degrade further.

FUNDING FOR FISCAL YEAR 2020

Sufficient resource allocations in fiscal year 2020 are required to address the massive hearings backlog, increased workloads, visitors, and telephone calls in field offices and to the National 800 Number, while at the same time maintaining deficit-reducing program integrity work. Resources are also necessary to advance SSA's efforts to undertake an Information Technology (IT) Modernization Plan that will significantly enhance the agency's systems and improve productivity. SSA must continue to modernize its computer language, databases and systems infrastructure. Although the fiscal year 2018 Consolidated Appropriations Act designated $280 million to support SSA's IT modernization efforts, without continued funding of SSA's IT needs in fiscal year 2020, there remains the risk for significant service disruptions and reduced system performance and production.

We very much appreciate that the House Appropriations Committee recognized the ongoing importance of advancing the agency's IT Modernization Plan while maintaining an appropriate balance between the service delivery options available to the public. In support of the following language, NCSSMA members nationwide are interested and willing to play an active role in development, testing and deployment of enhancements to existing systems in addition to new technology and programs.

Information Technology.—The Committee continues to monitor the Information Technology Modernization Plan and remains concerned that while SSA undertakes information technology upgrades and improvements, the agency must also maintain an appropriate balance between SSA's various service delivery options. As the agency continues to focus on modernizing information technology and systems, the Committee strongly encourages SSA to focus on enhancements that positively affect service to the public and add efficiency to administration of its programs. In addition, the Committee encourages involvement of agency front-line staff, those most familiar with the use of such programs, in all aspects of development, testing and deployment. The Committee requests an update of the plan referenced under this heading in House Report 114–699.

CONCLUSION

NCSSMA respectfully requests that Congress consider allocating at least $13.511 billion for SSA's LAE account in fiscal year 2020 to meet the agency's multitude of public service responsibilities. SSA must have the resources necessary to provide quality service to the American public, maintain program integrity efforts that save taxpayer dollars, and continue to address the high volumes of initial claims being filed and post-entitlement work.

On behalf of NCSSMA members nationwide, thank you for the opportunity to submit this written testimony. We respectfully ask that you consider our comments and would appreciate any assistance you can provide to ensure the American public receives the critical and necessary service they deserve from the Social Security Administration.

[This statement was submitted by Peggy Murphy, President, National Council of Social Security Management Associations.]

PREPARED STATEMENT OF THE NATIONAL COUNCIL OF URBAN INDIAN HEALTH

My name is Maureen Rosette and I am the President of the National Council of Urban Indian Health (NCUIH), which represents the 42 urban Indian healthcare organizations (UIOs) across the Nation who provide high-quality, culturally-competent care to urban Indians, constituting approximately 78 percent of all American Indians/Alaska Natives (AI/AN). I would like to thank both Chairman Blunt and Ranking Member Murray for holding this important hearing. My testimony today will focus on the needs of urban Indian organizations (UIOs).

As a preliminary issue, "urban Indian" refers to any AI/AN person who is not living on a reservation, either permanently or temporarily—often because of the Federal Government's forced relocation policy or in search of economic or educational opportunity. Congress has long recognized that the Federal Government's obligation to provide healthcare for AI/AN people follows them off of reservations. UIOs are an integral part of the Indian Health System (IHS), which is comprised of the IHS, federally recognized Tribes, tribal organizations, and urban Indian organizations (I/T/Us). Currently, UIOs receive less than 1 percent of the IHS budget, and the IHS budget is currently underfunded at less than 50 percent of need creating serious budget constraints. UIOs do not have access to many of the critical cost saving programs available to the other facets of the I/T/U system.

It is because of this historical underfunding that NCUIH advocates and supports an increase in funding to a minimum of $81 million—$116 million for the Indian Health Services (IHS) urban Indian healthcare line item, constituting 2 percent of the total IHS budget. The Indian Health Services funding is authorized under the Indian Health Care Improvement Act (IHCIA) [25 U.S.C. § 160 et seq.] amended and permanently reauthorized by the Patient Protection and Affordable Care Act (ACA) [Public Law 111–148]. However, unlike IHS and federally recognized Tribes, who receive funding from all IHS line items, UIOs only receive funding from one source within the IHS budget—the urban Indian line item.

Listed are NCUIH's recommendations to the Senate Labor, Health and Human Services, Education, and Related Agencies Subcommittee on Fiscal Year 2020 Appropriations:

Include Urban Indians in Language for ALL Health Programs

When urban Indians are not specifically mentioned in programmatic language they are most often excluded from participating in such programs. Many programs in the Health and Human Services appropriations bills include language for Indian Tribes and Tribal organizations, but not for urban Indian organizations. Urban Indian Organizations are not considered Tribal organizations, which is a common misconception. Therefore, UIOs must be explicitly included to receive funding. Behavioral health grants, suicide prevention grants, and others. It is imperative UIOs receive parity for funding as UIOs rely on less than 1 percent of the Indian Health Service (IHS) funds, despite urban Indians being over 78 percent of the AI/AN population. UIOs also do not have access to other IHS line items like IHS and Tribal facilities. UIOs do not receive hospitals and health clinics money, purchase and referred care dollars, or IHS dental services dollars, and are not eligible for facilities dollars. UIOs operate from one line item in the IHS budget, 42 programs with $51.3 million. We know IHS is underfunded at around $3,000 per patient, we know for urban Indian health patients that number is less than $400 per patient.

Shutdown Impacts with Funding Uncertainties

When limited UIO funding is delayed or cut off during events such as a government shutdown, UIOs suffer greatly. IHS and funded programs must receive advance appropriations. AI/AN people healthcare should not be held hostage by unrelated government shutdowns.

For instance, Native American Lifelines of Baltimore is a small clinic that received three overdose patients during the last shutdown, two of which were fatal. They only receive $922k from IHS to operate two facilities, one in Baltimore, one in Boston. IHS only gives them $691 for mental health services for both facilities. The Indian Health Service system (I/T/U) should be provided with funding to ensure our patients don't suffer. NCUIH as part of the National Tribal Budget Formulation Workgroup, has continuously highlighted the dire threat of sequestration. Medicare, Medicaid, the Children's Health Insurance Program, and Department of Veterans Affairs—are largely exempt from sequestration. IHS should be given the same favorable treatment. IHS may be funded through what are known as discretionary dollars, but the Federal Government's responsibility for Native American healthcare is a trust responsibility, not discretionary. NCUIH requests that members of this committee support and share with their distinguished colleagues the importance of advanced appropriations for AI/AN healthcare.

Centers for Medicare and Medicaid Services

100 percent FMAP (Federal Medical Assistance Percentage) for UIOs: We support the preservation of Medicaid and request the Federal Government extend the 100 percent Federal Medical Assistance Percentage (FMAP) to urban Indian healthcare organizations (UIOs). The Medicaid service costs paid by the Federal Government is set by law at 100 percent for IHS and Tribes, but not for UIOs, because the law was enacted at the same time that UIOs were created. UIOs were created by Congress at the urging of Tribes to ensure their tribal citizens would receive appropriate healthcare off of reservations. The failure to provide UIOs with 100 percent FMAP harms facilities that do not already have access to many other resources, severely limiting services for patients. Unfortunately, CMS needs Congress to add

UIOs to Sec. 1905 (42 U.S.C. 1396[d]) of the Social Security Act to create parity. We ask that you correct this problem in fiscal year 2020. Receiving 100 percent FMAP has a huge impact on the financial stability of UIOs. One of NCUIH's two Oklahoma facilities (the only two UIOs in the country that get 100 percent FMAP) reported that in the event of a prolonged shutdown they could remain open for over a year; whereas 6 of 13 UIO-respondents reported they could only sustain normal operations for 1 month or less.

Exempt AI/AN from work requirements: Medicaid is vital for Indian Country, accounting for roughly 13 percent of the overall IHS budget. Moving Medicaid to a block grant system, as proposed in the fiscal year 2020 Budget Request, would devastate Indian health systems. We urge Congress to require CMS use the Medicaid definition of AI/AN as well as ensure AI/ANs are exempt from any mandatory work requirements in the Medicaid program. If the work requirements proposed in the fiscal year 2020 Budget Request are applied to AI/ANs, it in turn, would deprive the IHS system of Medicaid resources in direct contrary to Congressional intent in Section 1911 of the Social Security Act and frustrate the purpose of the Medicaid statute for Indian health. NCUIH urges Congress to maintain the program while expanding its reach and availability for AI/ANs.

SAMHSA

Tribal Behavioral Health Grants: We are pleased UIOs were included in the increased funding for fiscal year 2019. These grants have allowed Indian Country to address mental and substance abuse. We request the Committee double the size of the TBHG program to $80 million total.

Opioid Funding: SAMHSA has awarded grants of approximately $50 million to American Indian and Alaska Native tribes to address the opioid overdose epidemic in tribal communities due to the high rates of overdose seen in comparison to other races/ethnic groups and NCUIH is happy Congress provided Tribes with a set-aside for opioid funding. These concerns are also seen in urban Indian communities, with many States undercounting these numbers due to missed data collection processes. Unfortunately, these funding sources to support treatment in a culturally appropriate way were not available to UIOs, as the eligibility was not explicit to include them. In fiscal year 2020 it is imperative that funding for UIO efforts to combat this epidemic are put in place to increase access to mental health services and meet unmet needs, request at least $3 million in opioid dollars be directed for UIOs with continued support and additional funding for Tribes and Tribal organizations. AI/AN experience the second highest opioid overdose rates.

Health Resources & Services Administration (HRSA)

11 out of the 42 UIOs are HRSA facilities. More UIOs would like to become HRSA facilities but do not want to lose their identity as a UIO. Because UIOs were created as part of the trust obligation—Tribes, Tribal organizations and UIOs should be allowed to exclusively see AI/AN patients and qualify as a HRSA facility. HRSA exemptions are too narrow. NCUIH requests Tribes, Tribal organizations, and Urban Indian Organizations become a third exemption, in line with the trust obligation.

340B Program: The Administration is currently considering revamping this program, with indications it will restrict its application. Tribes, Tribal organizations and UIOs should be held harmless, as it could provide a significant barrier to access to care for urban AI/ANs

HHS

HHS Tribal Consultation Policy: HHS is currently reviewing its Tribal Consultation Policy. Department of Health and Human Services—which, with the exception of IHS, is not required to specifically consider or confer urban Indian organizations. NCUIH requests Congress create a HHS Confer Policy similar to IHS.

Administration of Native Americans (ANA)

ANA is instrumental in creating great health and cultural programs and we ask that rather than a $3 million cut, you increase it at least $5 million. ANA tackles many issues in a culturally-relevant way, it is vital to increase its funding.

Centers for Disease Control

Good Health and Wellness in Indian Country (GHWIC): The GHWIC program is CDC's single largest investment in Indian Country. The program funds a total of 35 Tribes and Tribal organizations to improve chronic disease prevention efforts, expand physical activity, and reduce commercial tobacco use. The fiscal year 2020 President's Budget proposes elimination of this program. NCUIH requests the Committee reject elimination of GHWIC and increase funding to $30 million for fiscal year 2020. NCUIH requests UIOs be directly eligible for the grants.

Opioid Funding: NCUIH appreciates Congress' efforts to combat opioid abuse by providing over $60 million to Tribes and Tribal organizations. However, UIOs were erroneously left out. We echo NIHB's recommendations for an increase in Tribal funding as well as ask for $10 million for UIOs, as over 78 percent of AI/AN live in urban settings.

Funding for HIV, Viral Hepatitis, and Sexually Transmitted Infections: NCUIH requests Tribes, Tribal organizations, and Urban Indian Organizations have a 10 percent set aside of funding.

CDC Prioritizing AI/AN Data: Request that AI/ANs to be oversampled in all primary data collection efforts to ensure a large enough sample size to report findings. CDC has repeatedly shared that AI/AN sample sizes are too small to be statistically significant and therefore left out of local, regional, and national data reports. AI/ANs face stark health disparities and without the data, CDC, Congress, the Administration and others cannot ensure adequate resources are allocated.

We thank the committee for its efforts towards prioritizing funding to Indian Country within the HHS budget and for holding this public witness hearing. The staff at NCUIH is available to follow up on any future inquires related to my testimony or other urban Indian healthcare issues of policy or service.

PREPARED STATEMENT OF THE NATIONAL ENERGY AND UTILITY AFFORDABILITY COALITION

The National Energy and Utility Affordability Coalition (NEUAC) is a leader in the fields of public policy, advocacy, energy, and poverty issues. Members of the organization include non-profit organizations, energy assistance programs, trade associations, tribal organizations, and utilities.

NEUAC currently serves more than 170 member organizations that span the Nation. NEAUC provides its members with the tools to support families and underserved populations including the elderly, disabled, veterans, and families with young children. It is our mission to reduce energy burden, especially for these vulnerable populations, and to improve energy affordability.

NEUAC bridges the gap between States, social service organizations, and government, and facilitates cooperation between utilities and community partners to better serve our neighbors in times of energy crisis.

SUMMARY OF REQUEST

The U.S. Low Income Home Energy Assistance Program (LIHEAP) is America's cornerstone energy safety net program, within the jurisdictional responsibility of the U.S. Senate Subcommittee on Labor, Health and Human Services, Education, and Related Agencies. LIHEAP is federally administered by the U.S. Department of Health and Human Services, Administration of Children and Families, Office of Community Services.

The current Administration has proposed elimination of LIHEAP for three consecutive years. This is unthinkable. Thousands of households in your States would be adversely impacted by such a decision. Many families are perched on the precipice of poverty, where a singular unexpected event has the potential to send the family budget spiraling. It takes only one lost job, one desperate diagnosis, or one unexpected financial crisis. Any unplanned misfortune has the potential to adversely affect a family's ability to manage their household budget.

LIHEAP was funded in fiscal year 2019 at $3.69 billion. The program was last authorized at $5.1 billion. With only one in every five eligible households served, even the maximum authorized funding would be inadequate to meet the need.

Congress has demonstrated that LIHEAP is a national priority and has repeatedly protected funding for the program. NEUAC thanks this Subcommittee and its members for their leadership and strong support for LIHEAP. We respectfully request your support again this year to improve funding for LIHEAP.

ELIGIBILITY FOR LIHEAP

LIHEAP provides support to households with very limited or fixed incomes that helps reduce their energy burden, which is the percentage of household income spent on utility needs. Congress has entrusted States to set income LIHEAP eligibility levels up to 60 percent of State median income or 150 percent of the Federal poverty guidelines. Because of funding constraints, many States set the bar substantially below these thresholds.

States are authorized to address heating or cooling assistance and crisis situations with LIHEAP funds. They also may target a portion of LIHEAP funds for residential weatherization to improve energy efficiency and affordability for qualified households.

DEMONSTRATION OF NEED

The need for LIHEAP is far greater than the Federal resources provided to serve these vulnerable families. The National Energy Assistance Survey demonstrated that LIHEAP recipients are forced to make unthinkable choices between necessities like food or medicine or heat for their homes. In situations like these, LIHEAP provides bill payment assistance to keep the lights and heating or cooling turned on. This type of direct assistance to maintain utilities and prevent shut-off is one way LIHEAP combats energy poverty, but it is not the only way.

LIHEAP is one of the very few funding resources that may be used to repair or replace home heating and cooling systems for eligible households. According to the National Energy Assistance Survey, more than 25 percent of LIHEAP households cannot afford to repair or replace their home's non-functioning air conditioning systems, and 20 percent cannot afford to repair or replace a non-functioning heating system.[1]

The inability to maintain utilities can be tragic. Remember the polar vortex. Remember the deadly heat waves. Unlike some other Federal assistance programs, being eligible for LIHEAP does not entitle a household to benefits. Funds are limited by the amount that Congress appropriates each year, despite unmet need.

Poverty is a pervasive issue in the Mississippi Delta, where economic mobility is worse than anywhere else in the developed world.[2] In December 2018, a Mississippi couple died from what is believed to be carbon monoxide poisoning. The couple was found lying next to each other in a small portable building that had no electricity. They had a small propane generator in the center of the house that they were using for power.[3]

A Maryland father and his seven children also died of carbon monoxide poisoning from a generator left on overnight to heat their home. According to reports, the father was struggling to provide for his family and could not afford to turn on his utility service.[4]

Stories such as these highlight the unmet need in a program that has borne multiple reductions and reallocations in the past decade, creating an untenable strain on those who implement the program and those who rely on LIHEAP for assistance.

FUNDING REQUEST

The House has proposed to increase LIHEAP by $150 million in fiscal year 2020, bringing total funding to $3.84 billion. NEUAC appreciates the unwavering bipartisan support for LIHEAP in Congress.

NEUAC urges the Senate committee to consider the program's current fiscal and humanitarian challenges and work with appropriators and HHS leadership to further increase the program's budget in fiscal year 2020. The Energy Policy Act of 2005 authorized LIHEAP at $5.1 billion. It would take even greater funding to adequately address the need and ensure access to safe, affordable energy for all. NEUAC requests that the committee consider these facts when making funding decisions for fiscal year 2020 and maximize the funds available for LIHEAP.

Thank you for the opportunity to express the views of the National Energy and Utility Affordability Coalition on this important matter. On behalf of the 6 million households annually served by LIHEAP and the millions more hardworking American families that could be served with improved funding, we appreciate your consideration.

[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 National Energy Assistance Directors' Association (NEADA), represents the State directors of the Low-Income Home Energy Assistance Program (LIHEAP). For fiscal year 2020 we are requesting the Subcommittee provide no less than $4.7 billion for LIHEAP, the same level as provided in fiscal year 2011. We believe that

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[1] https://neuac.org/news-room/press-releases/2019-national-energy-survey/.

[2] https://www.pbs.org/newshour/show/poverty-stricken-past-present-mississippi-delta.

[3] http://time.com/3773584/carbon-monoxide-family-poisoning/.

[4] https://www.apnews.com/4f3d55caf7be4dcab948c37ca0c6f44e.

this level of funding would achieve the objectives of a letter signed by 44 Senators on April 13, 2019 addressed to the Senate Appropriations Committee asking that “you continue to prioritize funding for this vital program in fiscal year 2020 to help ensure that it meets the needs of eligible low-income households and seniors.”

The funding request will allow States to restore program services to the level provided in fiscal year 2011 when LIHEAP was last funded at $4.7 billion. In that year, LIHEAP was able to help 6.9 million households and cover about 63 percent of the cost of their home heating with an average annual grant of $560. In contrast, in fiscal year 2019, program funding was about $3.7 billion, $1 billion less than the amount of funding provided in fiscal year 2011.

What difference did a cut of $1 billion in Federal funding make to low income families? The reduction in funding between fiscal year 2011 and fiscal year 2019 has had a significant and profound impact on the ability of LIHEAP to help poor families. First, the estimated number of families helped declined by about one million from 6.9 million to 5.9 million. Second, the estimated average annual grant was reduced from about $560 to $492. The average purchasing power during this time was also reduced from about 63 percent of the cost of home heating to 55 percent of the cost of home heating.

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 of LIHEAP without harming millions of very vulnerable households.

We would also like to thank the members of the subcommittee for increasing fiscal year 2019 LIHEAP funding by $50 million to $3.69 billion. The additional funding has allowed States to help families facing shut-off of utility service and pay off higher heating oil and propane bills as a direct result of higher prices and colder winter conditions. In addition, the funding will help States increase assistance for cooling programs this summer.

PRICE OF HOME HEATING REMAINS UNAFFORDABLE

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 $918, representing an increase of $30 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 increased from $1,534 to $1,604, heating oil from $1,376 to $1,520, electricity from $1,144 to $1,174 and natural gas from $565 to $584.

REJECT THE ADMINISTRATION’S BUDGET

The Administration’s Budget, if enacted, would eliminate all funding for LIHEAP beginning in fiscal year 2020. 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 position is based on two points: the first is that the program should be eliminated because of a nine-year old GAO study that reported isolated cases of fraud and the second is that States have enacted shut-off provisions during winter heating and summer cooling cycles.

The State LIHEAP directors strongly disagree with both of the Administration’s positions and urge the members of the Subcommittee to reject the Administration’s proposal. First, the States have been working in partnership with the Administration for Children and Families (ACF) to implement a comprehensive performance measures program. As part of this program, States 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 preventing loss of energy services.

Second, 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. Without LIHEAP, energy assistance is unreliable, especially during periods of price spikes due to global events or extreme weather that make home energy unaffordable. State, local, and utility programs are not a substitute for LIHEAP, rather they provide supplementary assistance.

In addition, shut-off protections do not eliminate the necessity of a poor family paying their energy bill—they simply delay the due date. Thefamily will still be responsible for the full bill once the shut-off moratorium expires. And for those families using unregulated delivered fuels—heating oil and propane—there are no shut-off protections.

FUNDING IS SUFFICIENT TO SERVE ONLY A FRACTION OF THE ELIGIBLE POPULATION

LIHEAP is the primary source of heating and cooling assistance for some of the poorest families in the United States. In fiscal year 2019, the number of households receiving heating and cooling assistance is expected to remain at about 5.9 million or about 19 percent of eligible households, with an average annual grant size of about $513. 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.

ENERGY PRICES AND THEIR IMPACT ON LOW INCOME HOUSEHOLDS

Energy prices fall hardest on lower income households. 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.

HOW LIHEAP HELPS FAMILIES

In December NEADA completed a survey of LIHEAP recipients, the 2018 National Energy Assistance Survey, Final Report (http://neada.org/program-policy-reports/liheapsurvey/). The survey asked recent LIHEAP recipients in seven States selected for national representation how they fared prior to receiving LIHEAP grants. Of 634 respondents:

—37 percent had closed off part of their home to save utility costs
—25 percent kept the temperature inside unsafe or unhealthy
—52 percent of households have a disabled member, many of whom rely on electricity for breathing machines or to refrigerate medicines
—17 percent had to move in with friends or family and 6 percent went into shelters.

The study further found that the poor are hit hard by energy bills, which take about 12 percent out of a low-income paycheck, but only 2.7 percent from households with higher wages. In winter the heating bill can cost a low-income family 25 percent of its income. Only 26 percent of LIHEAP respondents reported being unemployed part of a year, yet in order to try to meet their utility costs:

—36 percent went without food for at least a day
—41 percent went without medical or dental care
—31 percent did not fill a prescription or took less than a prescribed dose to stretch their supply.

These responses from LIHEAP recipients underline the agonizing choices faced by low-income households that struggle to pay their utility bills. In 2015 the U.S. Energy Administration reported that nearly one third of all American households struggle to pay energy bills, with 25 million foregoing food and medicine to pay for utilities, and 7 million households facing that decision every month.

PLAYING A CRUCIAL ROLE IN MAINTAINING FAMILY STABILITY AND POSITIVE HEALTH OUTCOMES

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.

The following are several examples of households receiving LIHEAP assistance and how LIHEAP helped the families stay connected to essential energy services:

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.

Colorado.—A mother of three is raising her children on her own because her husband had a stroke and is now confined to a care facility. Her car was repossessed so she was no longer able to report to work and lost her job. She received a shutoff notice for her heat and could not allow her children to suffer in the cold. She reached out to the State LIHEAP Office and was able to obtain the assistance she needed to get her heat bill back on track.

An elderly woman's furnace stopped working around Thanksgiving. She had no spare money to repair or replace it. She reached out to the State LIHEAP Office. Her application was approved, making her eligible for the Crisis Intervention Program. Her furnace was repaired and in working order within one day of being approved for LIHEAP.

A man is caring for his elderly mother. Her furnace broke and she had been heating her home with her oven. Neither the man nor the woman could afford a new furnace, so the man helped his mother apply for LIHEAP. Her new furnace was installed within days.

District of Columbia.—A 79-year-old lifelong DC resident nearly gave up her home in the historic Anacostia neighborhood when her gas service was disconnected. She received LIHEAP assistance from the DC Department of Energy and Environment (DOEE), as well as an ongoing utility bill discount, a new heating system, and had a major leak in the basement fixed through pro bono work offered by a local company in partnership with a nonprofit organization.

Florida.—A father with two children was working to manage his wife's medical care and the household needs. After his wife died, he left work to take care of his daughters, one of whom suffers from epilepsy. He fell behind on his electric bill and was in danger of being disconnected. LIHEAP funds helped keep the power on and pay down his overdue balance.

Georgia.—A 77-year-old disabled senior living on Social Security was facing shutoff due to unaffordable winter energy bills. She had to maintain a consistent home temperature due to her frail health. Her gas bill was in danger of disconnection with a balance of $612 and an additional past due portion of $355. She found she was eligible for both the LIHEAP maximum benefit of $350 and Home Energy Assistance Team program funds of $350, allowing her to bring her home heating bill current so she could heat her home through the rest of the winter.

Illinois.—A 58-year-old terminally ill man was facing electricity shutoff due to a large past-due electric account balance that he could not pay after he covered his rent and medical bills. He did not think he was eligible for LIHEAP because he received a benefit earlier in the year. He applied for the LIHEAP crisis assistance benefit, and LIHEAP assisted him the same day.

Indiana.—A retired police officer known in the community for helping those less fortunate than himself had been using space heaters to heat his home since his furnace had stopped working 2 years prior. The space heaters were not keeping the home at a comfortable temperature. His son encouraged him to apply for LIHEAP for help. In addition to receiving a LIHEAP benefit, the retired officer received a new furnace using LIHEAP funds.

Minnesota.—An older man, living alone with a disability in rural Minnesota came into the local LIHEAP office. He broke down in tears as he explained that he had always been self-sufficient, but that he now has ALS and reluctantly is seeking help to pay his heating bill. With his medical bills and medication costs, he struggled to keep up and was facing having his heat shut off. In Minnesota, heat is a basic necessity. LIHEAP assistance helped him stay safe and in his home.

An elderly couple in northern Minnesota was assisted by LIHEAP to help pay their heating bill. The LIHEAP assistance allowed them to use their limited funds to pay for other things essential to their health and safety, including prescription medication and food.

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.

NEADA strongly urges the Congress to reject the Administration's proposal and instead increase funding to at least $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.

[This statement was submitted by Mark Wolfe, Executive Director, National Energy Assistance Directors' Association.]

PREPARED STATEMENT OF THE NATIONAL FAMILY PLANNING & REPRODUCTIVE HEALTH ASSOCIATION

Chairman Blunt, Ranking Member Murray, and Subcommittee Members:

Thank you for this opportunity to provide testimony in support of increased Title X funding in the fiscal year 2020 appropriations bill. I am deeply concerned by the administration's continued attacks on the integrity of the Title X program, as demonstrated by the devastating rule published by the administration on March 4,[1] and by the continued underfunding of the Nation's only Federal program dedicated to family planning and sexual health services for people who are low-income, uninsured, or underinsured. I urge the Senate to provide strong support for Title X's high-quality, evidence-based, and patient-centered care by adopting the House's appropriation of $400 million and language protecting the program's integrity in the fiscal year 2020 Labor, Health and Human Services, Education, and Related Agencies appropriations bill.

The National Family Planning & Reproductive Health Association (NFPRHA) is a non-partisan 501(c)3 membership association that advances and elevates the importance of family planning in the Nation's healthcare system and promotes and supports the work of family planning providers and administrators, especially in the safety net. Representing more than 850 members that operate or fund more than 3,500 health centers in the United States, NFPRHA conducts and participates in research; provides educational subject matter expertise to policy makers, healthcare providers, and the public; and offers its members capacity-building support aimed at maximizing their effectiveness and financial sustainability as providers of essential healthcare. NFPRHA represents more than 70 percent of Title X grantees and more than 90 percent of Title X service sites.

Title X helps more than four million people access family planning and related health services at nearly 4,000 health centers around the country annually.[2] Title X-funded health centers include a diverse array of providers, such as State and local health departments, freestanding family planning centers, Planned Parenthood affiliates, federally qualified health centers, hospitals, school- and university-based health centers, a diversity that allows patients to seek care at the site that works best for them.

For many individuals, particularly those who have low incomes, are under- or uninsured, or are adolescents, Title X-supported sites are their main access point to affordably and confidentially obtain contraception, cancer screenings, sexually transmitted disease testing and treatment, complete and medically accurate information about their sexual health and family planning options, and other basic care. In fact, a 2017 study found six in ten women seeking contraceptive services at a Title X health center saw no other healthcare providers that year.[3] In addition to that direct clinical care, Title X supports important health center efforts that are not reimbursable under Medicaid or private insurance, including critical staff training and community-based sexual and reproductive health education programs.

Despite this compelling data, and in spite of the critical importance of equitable access to family planning services for all people, Title X has remained woefully underfunded at just over $286 million for the past 6 years. In 2016, researchers from the Centers for Disease Control and Prevention, the Office of Population Affairs, and George Washington University estimated that Title X would need $737 million annually to deliver family planning care to all uninsured, low-income women in the United States.[4] This estimate understates the true need for Title X, as it does not

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[1] Department of Health and Human Services. Final Rule. "Compliance with Statutory Program Integrity Requirements." Federal Register 84 (March 4, 2019): 7714–7791.

[2] Christina Fowler et al, "Family Planning Annual Report: 2017 National Summary," RTI International (August 2018). https://www.hhs.gov/opa/sites/default/files/title-x-fpar-2017-national-summary.pdf.

[3] Mia Zolna, Megan Kavanaugh, and Kinsey Hasstedt. "Insurance-Related Practices at Title X-Funded Family Planning Centers under the Affordable Care Act: Survey and Interview Findings." Guttmacher Institute (November 2017). https://www.guttmacher.org/article/2017/11/insurance-related-practices-title-x-funded-family-planning-centers-under-affordable.

[4] Euna August, et al, "Projecting the Unmet Need and Costs for Contraception Services After the Affordable Care Act," American Journal of Public Health (February 2016): 334–341.

include an estimate of costs for men (who made up 12 percent of patients in the network in 2017[5]), does not account for Title X's trans and nonbinary patients, and does not include an estimate for the insured patients who rely on Title X's confidentiality protections.

The gap between the funds appropriated and the funds needed has only grown in recent years. From 2010 to 2014 the number of women who needed publicly funded family planning services increased by one million,[6] but Congress cut Title X's funding by $31 million over that period. That decrease unfortunately corresponds to dramatic decreases in the number of patients served at Title X-funded sites; the numbers dropped from 5.22 million in 2010[7] to just over four million in 2017.[8]

In April, the House Appropriations Committee recognized these challenges and adopted NFPRHA's recommendations to strengthen the Title X program by including an appropriation of $400 million and new language to block the harmful Title X rule finalized in March and restore the full regulatory framework for Title X to its 2016 status. NFPRHA urges you to adopt these critical provisions in your bill and maintain existing requirements that support the program's ability to fulfill Congress' vision for this essential public health program.

These funding and language requests come in the wake of a final rule from the administration that is unlawful, coercive, and dangerous for patients' health. On March 4, the administration published a final rule[9] that disregards medical ethics and Federal guidelines in order to severely restrict the providers in the Title X network and the care that patients can receive from those remaining in the program. Federal judges in Washington, Oregon, and California responded swiftly to the potential illegality of the new rules by issuing injunctions against the rule in April 2019.[10] While these cases work their way through the court system, I urge you to use your power to block the rules through the appropriations bill.

Thousands of providers and millions of patients are counting on Congress to stand strong against attacks on family planning and support increased public funding for the Title X program. I look forward to working with committee members in those efforts.

If you have questions about this testimony, please contact my colleague Lauren Weiss, Director, Advocacy & Communications, at lweiss@nfprha.org.

[This statement was submitted by Clare Coleman, President & CEO, National Family Planning & Reproductive Health Association.]

PREPARED STATEMENT OF THE NATIONAL FIREFIGHTER CANCER REGISTRY

Dear Chairman Blunt and Ranking Member Murray,

On behalf of the Nation's fire and emergency services, we write to urge your support for a vital program addressing the health and safety of our Nation's firefighters. As you consider the fiscal year 2020 Labor, Health and Human Services, Education, and Related Agencies Appropriations bill, we urge you to fully fund the Firefighter Cancer Registry at the authorized level of $2.5 million.

During the 115th Congress, both the House and Senate unanimously approved the Firefighter Cancer Registry Act (Public Law 115–194). The bipartisan legislation created a specialized national registry to provide researchers and epidemiologists with the tools and resources needed to improve research collection activities related to the monitoring of cancer incidence among firefighters.

Studies have indicated a strong link between firefighting and an increased risk of several major cancers. However, certain studies examining cancer risks among firefighters have been limited by the availability of important data and relatively

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[5] Christina Fowler et al, "Family Planning Annual Report: 2017 National Summary," RTI International (August 2018). https://www.hhs.gov/opa/sites/default/files/title-x-fpar-2017-national-summary.pdf.

[6] Jennifer Frost, Lori Frohwirth and Mia Zolna, "Contraceptive Needs and Services, 2014 Update," Guttmacher Institute (September 2016). https://www.guttmacher.org/report/contraceptive-needs-and-services-2014-update.

[7] Christina Fowler et al, "Family Planning Annual Report: 2017 National Summary," RTI International (August 2018). https://www.hhs.gov/opa/sites/default/files/title-x-fpar-2017-national-summary.pdf.

[8] Fowler et al, "Family Planning Annual Report: 2016 National Summary."

[9] Department of Health and Human Services. Final Rule. "Compliance with Statutory Program Integrity Requirements." Federal Register 84 (March 4, 2019): 7714–7791.

[10] See State of Washington v. Alex M. Azar II., No. 1:19-cv-03040–SAB (E.D. Wash. Apr. 25, 2019), American Medical Ass'n et al. v. Alex M. Azar II, et al., No. 6:19-cv-00317–MC (D. Or. Apr. 29, 2019), Essential Access Health, Inc. et al. v. Alex M. Azar, et al., No. 19-cv-01195–EMC (N.D. Cal. Apr. 26, 2019).

small sample sizes that have an underrepresentation of women, minorities, and volunteer firefighters. As a result, public health researchers are unable to fully examine and understand the broader epidemiological cancer trends among firefighters. The Firefighter Cancer Registry is an important resource to better understand the link between firefighting and cancer, potentially leading to better prevention and safety protocols.

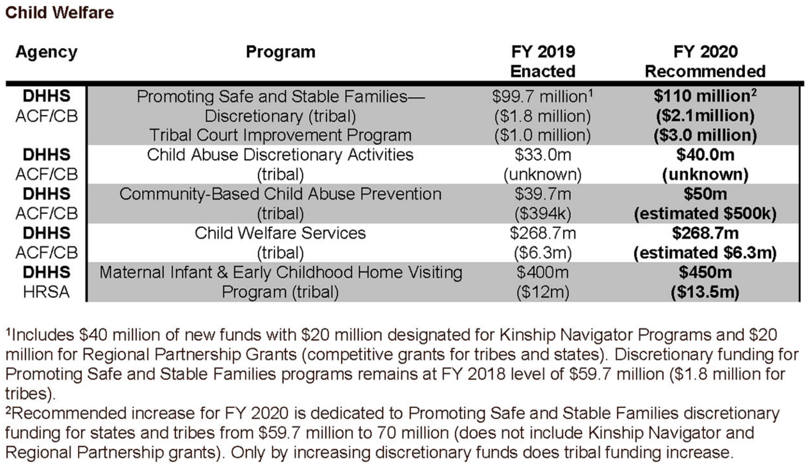
Thank you for your consideration, and your continued leadership and support for America's fire and emergency services.

Sincerely,

Congressional Fire Services Institute
International Association of Arson Investigators
International Association of Fire Chiefs
International Association of Fire Fighters
International Fire Service Training Association
International Society of Fire Service Instructors
National Fallen Firefighters Foundation
National Fire Protection Association
National Volunteer Fire Council

PREPARED STATEMENT OF THE NATIONAL INDIAN CHILD WELFARE ASSOCIATION

The National Indian Child Welfare Association (NICWA), located in Portland, Oregon, has over 35 years of policy experience advocating on behalf of American Indian and Alaska Native (AI/AN) children in child welfare and children's mental health systems. Thank you for the opportunity to provide fiscal year 2020 budget recommendations for child welfare and children's mental health programs administered by the Department of Health and Human Services (DHHS). Our full recommendations appear in the charts below with our priority recommendations described in more detail underneath the charts.



Child Welfare

Agency	Program	FY 2019 Enacted	FY 2020 Recommended
DHHS ACF/CB	Promoting Safe and Stable Families— Discretionary (tribal) Tribal Court Improvement Program	\$99.7 million[1] (\$1.8 million) (\$1.0 million)	**\$110 million[2]** **(\$2.1million)** **(\$3.0 million)**
DHHS ACF/CB	Child Abuse Discretionary Activities (tribal)	\$33.0m (unknown)	**\$40.0m** **(unknown)**
DHHS ACF/CB	Community-Based Child Abuse Prevention (tribal)	\$39.7m (\$394k)	**\$50m** **(estimated \$500k)**
DHHS ACF/CB	Child Welfare Services (tribal)	\$268.7m (\$6.3m)	**\$268.7m** **(estimated \$6.3m)**
DHHS HRSA	Maternal Infant & Early Childhood Home Visiting Program (tribal)	\$400m (\$12m)	**\$450m** **(\$13.5m)**

[1] Includes $40 million of new funds with $20 million designated for Kinship Navigator Programs and $20 million for Regional Partnership Grants (competitive grants for tribes and states). Discretionary funding for Promoting Safe and Stable Families programs remains at FY 2018 level of $59.7 million ($1.8 million for tribes).

[2] Recommended increase for FY 2020 is dedicated to Promoting Safe and Stable Families discretionary funding for states and tribes from $59.7 million to 70 million (does not include Kinship Navigator and Regional Partnership grants). Only by increasing discretionary funds does tribal funding increase.

PRIORITY RECOMMENDATIONS

Promoting Safe and Stable Families recommendation (Title IV–B, Subpart 2–Discretionary Portion).—Increase discretionary funding under this program to $70 million (not including Kinship Navigator and Regional Partnerhip grants at $40 million) to provide additional access to tribes who are currently not eligible to apply for these funds based upon the current eligibility criteria that are tied to the funding formula, and increase tribal court improvement funding to $3 million.

The Promoting Safe and Stable Families Program provides funds to tribes for coordinated child welfare services that include family preservation, family support, family reunification, and adoption support services. This program has a mandatory capped entitlement appropriation as well as a discretionary appropriation. There is a 3 percent set-aside for tribes under each program. All tribes with approved plans are eligible for a portion of the set-aside that is equal to the proportion of their member children compared to the total number of member children for all tribes with approved plans. Based on this formula, tribes who would qualify for less than $10,000 are not eligible to receive any funding. This means that many tribes, typically those tribes that are most in need, cannot access it because the overall appropriation is currently too low. Out of the 573 federally recognized tribes, over 100 tribes have no access to these funds.

Tribal systems endeavor to reduce out-of-home placements whenever possible, saving children and their families additional trauma and helping Sstates 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 homess—as opposed to receiving family preservation services—than their non-Native counterparts.[3] 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.[4] New prevention services funding under Title IV–E will help a small portion of tribes, typically those that already receive Promoting Safe and Stable Funding, but many smaller tribes do not have access to Title IV–E and rely on these kinds of funds to reduce out of home placements and stabilize families.

The Promoting Safe and Stable Families Program offers support for culturally based services that tribes already have experience with, such as parenting classes, home visiting services, and respite care for caregivers of children. This program is vital to the tribes that depend on it to support efforts to prevent the unnecessary removal of AI/AN children from their homes.

Tribes are also eligible to apply for the Tribal Court Improvement Program, a competitive grant program authorized under Promoting Safe and Stable Families. This program is authorized for $30 million of mandatory funding plus 3.3 percent of all discretionary funds. A $1 million tribal set-aside was created in the 2011 Child and Family Services Improvement and Innovation Act, Public Law No. 112–34 (2011). Seven tribal court improvement project grantees are currently funded under this program. They are using these funds to strengthen their family courts and better integrate the work of their courts with their child welfare systems and with their State court partners who serve Native children and families under their jurisdiction.

Community-Based Child Abuse Prevention grants: Increase overall appropriations to $50 million to increase funding available under the tribal set-aside for additional tribal grants.

Community-Based Child Abuse Prevention grants provide funding for primary and secondary child abuse prevention activities. The funds are often used to support community-wide child abuse prevention campaigns, provide education on how to lower risk of child abuse and neglect, and connect families with supportive services to keep children safe. These funds can also be key to reducing foster care placement rates and supporting tribes in their role as partners to States who may have AI/AN children in their care.

While many tribes are interested in developing culturally-based child abuse and neglect prevention efforts, tribes share a 1 percent set-aside under the grant program with migrant populations which funds between 2–3 tribal grants each three-year grant cycle. This limited funding has severely hampered the building of a critical knowledge base and successful programming in Indian Country.

An accurate understanding of successful child abuse and neglect interventions for American Indian and Alaska 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.[5]

Increasing tribal funding under this program is the surest way to increase effective responses to child abuse and neglect in tribal communities.

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[3] Hill, R. B. (2008). An analysis of racial/ethnic disproportionality and disparity at the national, State, and county levels (p. 9). Seattle, WA: Casey Family Programs, Casey-CSSP Alliance for Racial Equity in Child Welfare, Race Matters Consortium Westat.

[4] National Child Welfare Resource Center for Tribes. (2011). Findings from the national needs assessment of American Indian/Alaska Native child welfare programs (p. 23). Retrieved from nrc4tribes.org/files/NRCT%20Needs%20Assessment%20Findings__APPROVED.pdf.

[5] U.S. Department of Justice, Office of Justice Programs, Office of Juvenile Justice and Delinquency Prevention. (2014). Attorney General's Advisory Committee on American Indian/Alaska Native Children Exposed to Violence: Ending violence so children can thrive (p. 81). Retrieved from www.justice.gov/sites/default/files/defendingchildhood/pages/attachments/2014/11/18/finalaianreport.pdf.

Children's Mental Health

Agency	Program	FY 2019 Enacted	FY 2020 Recommended
DHHS SAMHSA	Programs of Regional and National Significance—Children and Family Programs (includes Circles of Care)	$7.2 million (no funds reserved for Circles of Care)	**$7.2 million (Reserve $6.5m for Circles of Care)**
DHHS SAMHSA	Children's Mental Health Services Program— Systems of Care	$125m (no funding reserved for state or tribal System of Care grants)	**$135m (Reserve funding for state and tribal children's mental health grants)**
DHHS SAMHSA	GLS State/Tribal Youth Suicide Prevention (tribes receive portion of grant funds)	$35.4m	**$40.5m**
DHHS SAMHSA	GLS Campus Suicide Prevention Program	$6.5m	**$9.1m**
DHHS SAMHSA	AI/AN Suicide Prevention	$2.2m	**$4.0m**
DHHS SAMHSA	Tribal Behavioral Health Grant (divided between substance abuse prevention and mental health services)	$20m	**$50m**

Programs of Regional and National Significance, Children and Family Programs (includes Circles of Care).—Ensure that $6.5 million under this line item continues to be reserved specifically for the tribal and urban Indian community Circles of Care program in fiscal year 2020.

The Children and Family Programs under Programs of Regional and National represents funds allocated to support the tribal Circles of Care program. Circles of Care is a competitive grant program exclusively for tribal communities. It is the cornerstone of tribal children's mental health programming.

Circles of Care is a three-year planning grant that helps communities design programs to specifically serve AI/AN children with serious behavioral health issues. Specifically, Circles of Care funds the development of the tribal capacity and infrastructure necessary to support a coordinated network of holistic, community-based, mental and behavioral health interventions in tribal communities.

Circles of Care is one of only two SAMHSA programs that allow tribes and tribal organizations to apply for funding without competing with other governmental entities (States, counties, or cities). There are currently 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.[6] Since its inception in 1998, the Circles of Care program has affected 49 different tribal and urban Indian communities. These programs have been incredibly successful. The majority of tribes who have received these grants have created long-term, sustainable systems of care for their children.

Of the 31 total graduated Circles of Care grantees, 12 have obtained direct funding to implement their system change efforts through System of Care (SOC) grants, and four others have partnered with other SOC grantees to implement their models. The others have developed various alternative strategies to operationalize and sustain their system change plans to care for youth with mental health challenges.

Children's Mental Health Initiative (Systems of Care).—Continue funding at $125 million to allow for continued support of the current four-year grantees and funding of new grantees in fiscal year 2020. We are asking for Congress to specify that these funds must be used for System of Care grants for States and tribes.

The children's mental health initiative supports the development of comprehensive, community-based "systems of care" for children and youth with serious emotional disorders. This includes funding for 1 year System of Care Expansion Planning Grants, four-year System of Care Expansion Implementation Grants, and six-year Children's Mental Health Initiative System of Care Grants. AI/AN communities are eligible for, and recipients of, each of these grants, but must compete with non-tribal applicants to receive these funds.

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[6] American Psychiatric Association. (2010). Mental health disparities factsheet: American Indians and Alaska Natives (p. 4).

Children's Mental Health Initiative System of Care Grants support a community's efforts to further plan and implement strategic approaches to mental health services. These approaches are based on important principles: they must be family-driven; youth-guided; and meet the intellectual, emotional, cultural, and social needs of children and youth. Since 1993, 180 total projects have been funded, dozens of which have been in tribal communities. Currently, 12 tribal communities are funded.

Evaluation studies of System of Care have indicated return on investment from cost-savings in reduced use of in-patient psychiatric care, emergency room care, and residential treatment even when other community- or home-based care is provided. There are also cost savings from decreased involvement in juvenile justice systems, fewer school failures, and improved family stability.[7]

Programs of Regional and National Significance, Tribal Behavioral Health Program.—Increase funding for the Tribal Behavioral Health program (mental health and substance abuse prevention programs) to $50 million in fiscal year 2020.

In the fiscal year 2019, the Tribal Behavioral Health Grants were funded at $20 million ($20 million in the Mental Health appropriation and $20 million in the Substance Abuse Prevention appropriation). NICWA recommends $50 million in fiscal year 2020 to continue to address the expansion of suicide prevention, mental health, and substance abuse activities for Native communities.

These are competitive grants designed to target tribal entities with the highest rates of suicide per capita over the last 10 years. These funds must be used for effective and promising strategies to address the problems of substance abuse and suicide and promote mental health among AI/AN young people.

AI/AN young people are more likely than other youth to have an alcohol use disorder. In 2007, 8.5 percent of all AI/AN youth struggled with alcohol use disorders compared to 5.8 percent of the general youth population.[8] Although these statistics are troubling, with adequate resources tribes are best able to serve these young people and help them heal before they reach adulthood:

There is growing evidence that Native youth who are culturally and spiritually engaged are more resilient than their peers. Research has revealed that 34 percent of Native adolescents preferred to seek mental or substance abuse services from a cultural- or religious-oriented service provider. In other research, American Indian caregivers preferred cultural treatments (e.g., sweat lodge, prayer) for their children and found the traditionally based ceremonies more effective than standard or typical behavioral health treatment.[9]

PREPARED STATEMENT OF THE NATIONAL INDIAN HEALTH BOARD

Chairman Blunt, Ranking Member Murray, and Members of the Subcommittee, thank you for the opportunity to offer this testimony. On behalf of the National Indian Health Board (NIHB) and the 573 Tribal Nations we serve, I submit this testimony for the record on the fiscal year 2020 budget for the Department of Health and Human Services (HHS).

Since the earliest days of the Republic, all branches of the Federal Government have acknowledged the Nation's constitutional obligations to Tribal Nations and the special trust relationship between the United States Government and Tribal Governments. This duty was reaffirmed in 2010 with the permanent reauthorization of the Indian Healthcare Improvement Act, in which Congress declared "... it is the policy of this Nation, in fulfillment of its special trust responsibilities and legal obligations to Indians—to ensure the highest possible health status for Indians and urban Indians and to provide for all resources necessary to effect that policy."[1]

Congress again affirmed this special relationship with Tribes in the fiscal year 2019 Labor, Health and Human Services, Education, and Related Agencies (Labor-HHS) Committee Report when it stated, "...Indian Tribes are political, sovereign en-

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[7] Stroul, B. (2015). Return on investment on System of Care for children with behavioral health challenges: A look at wraparound. The TA Telescope, 1(2), pp. 1–2.

[8] 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.

[9] Novins, D. K., & Bess, G. (2011). 10. Systems of mental healthcare for American Indian and Alaska Native children and adolescents. In P. Spicer, P. Farrell, M. C. Sarche, & H. E. Fitzgerald (Eds.), American Indian and Alaska Native children and mental health: Development, context, prevention, and treatment. Santa Barbara, CA: SABC-CLIO, LLC.

[1] 25 U.S.C. 1602.

tities to which the Federal Government owes a trust responsibility. Congress has routinely codified this relationship, most notably in the provision of healthcare by establishing a health system for Tribal populations exclusively."[2] The Indian Health Service (IHS) was established in part to fulfill the Federal Government's trust responsibility for health; however, IHS has never been fully funded at the level of need. For example, in fiscal year 2017, IHS per capita expenditures for medical care amounted to just $4,078, compared to $9,726 nationally.[3] While full funding for IHS remains a top priority for Tribal Nations, fulfilling the Federal trust responsibility for health is the obligation of every Federal agency—not just IHS.

NIHB would first like to thank the Committee for increasing funding for Tribes and Tribal organizations within the fiscal year 2019 Labor-HHS Appropriations Act. These included a $50 million set aside for Tribal Opioid Response (TOR) grants; $21 million for Good Health and Wellness in Indian Country (GHWIC); and $40 million for Tribal Behavioral Health Grants.

Nevertheless, much more work needs to be done. Tribal health systems are often left out of larger public health and behavioral health grants and block grants that flow to States. While Tribes are eligible to apply for these grants, many have little penetration into Indian Country because Tribes have difficulty meeting the service population requirements, match requirements, or are under-resourced to apply. Instead, funding should flow to Tribes directly on a recurring, formula basis, so that Tribes can count on funding from year to year. Direct funding to Tribes and Tribal organizations honors the Federal trust responsibility and the inherent sovereignty of Tribal Nations, and ensures that Tribes have the necessary resources to improve the health and wellness of their Peoples.

CENTERS FOR DISEASE CONTROL AND PREVENTION

Preventive Health and Health Services Block Grant (PHHSBG): Tribal public health infrastructure and capacity is significantly lower than that of States and counties, because Tribes were left behind during the Nation's development of its public health infrastructure. As a result, Tribal health systems generally lack the capacity to conduct robust disease surveillance and tracking, engage in preparedness and disaster relief efforts, and provide comprehensive preventive health services. The fiscal year 2020 President's Budget proposes total elimination of PHHSBG. While only two Tribes receive a small portion of these funds, it is vital that this program be maintained and its reach in Indian Country expanded. NIHB requests that, in fiscal year 2020, Congress maintain PHHSBG funding at $160 million and provide a direct, annual set aside of 5 percent for Tribes and Tribal organizations.

Good Health and Wellness in Indian Country (GHWIC): The GHWIC program is CDC's single largest investment in Indian Country. The program funds a total of 35 Tribes and Tribal organizations to improve chronic disease prevention efforts, expand physical activity, and reduce commercial tobacco use. NIHB is thankful to the Committee for including a $5 million increase to GHWIC for fiscal year 2019. However, the fiscal year 2020 President's Budget proposes elimination of this program. NIHB requests that the Committee reject elimination of GHWIC and increase funding to $32 million for fiscal year 2020.

Funding for HIV, Viral Hepatitis, and Sexually Transmitted Infections: Tribal communities are disproportionately impacted by HIV, viral hepatitis, and sexually transmitted infections (STIs). According to the CDC, rates of new HIV infections increased by 81 percent among gay and bisexual AI/AN men from 2010 to 2016,[4] while AI/ANs continue to have the highest Hepatitis C mortality rates nationwide at 10.8 deaths per 100,000 in 2016.[5] Furthermore, gonorrhea rates among AI/ANs are 4.5 times higher than for Whites, while rates of chlamydia and syphilis are 2.7 and 2.1 times higher respectively.[6] Nevertheless, in fiscal year 2018, no Tribe or Tribal organization received STI or viral hepatitis prevention grants from CDC, and only two community-based organizations serving AI/ANs received HIV dollars. The fiscal year 2020 Budget Request includes a new $140 million investment in CDC to further the President's announcement of ending the HIV epidemic by 2030. NIHB requests that

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[2] fiscal year 2019 House Labor-HHS Committee Report.

[3] National Tribal Budget Formulation Workgroup's Recommendations on the Indian Health Service fiscal year 2021 Budget.

[4] CDC. (2019). HIV and American Indians and Alaska Natives. Retrieved from https://www.cdc.gov/hiv/pdf/group/racialethnic/aian/cdc-hiv-aian-fact-sheet.pdf.

[5] CDC. Surveillance for Viral Hepatitis: United States, 2016. Retrieved from https://www.cdc.gov/hepatitis/statistics/2016surveillance/commentary.htm.

[6] CDC. Sexually Transmitted Disease Surveillance, 2017. Retrieved from https://www.cdc.gov/std/stats17/natoverview.htm.

the Committee provide direct 5 percent set asides in HIV, viral hepatitis, and STI funding for Tribes and Tribal organizations.

SUBSTANCE ABUSE AND MENTAL HEALTH SERVICES ADMINISTRATION

Substance Abuse Prevention and Treatment Block Grant (SABG): The SABG is one of two major block grants administered by SAMHSA, the other being the Community Mental Health Services Block Grant (MHBG). Tribes are not eligible to receive MHBG grants, which contributes to the dearth of mental health services available within Tribal communities. While all 50 States, the District of Columbia, and eight U.S. territories receive SABG funding, only 1 Tribe is included. Increasing Tribal access to SABG is critical towards building Tribal behavioral health capacity and reducing Tribal behavioral and mental health disparities. NIHB requests that the Committee set aside SABG funding for Tribes and Tribal organizations and work with authorizing committees to extend eligibility for MHBG funding to Tribes.

Tribal Behavioral Health Grants: NIHB was pleased to see both the mental health and substance abuse TBHGs increased to $20 million each for fiscal year 2019 ($40 million total). These two Tribally-focused programs have created over 140 unique projects in Indian Country addressing a wide variety of mental and behavioral health needs, and have helped many Tribes address chronic shortages in mental and behavioral health services. NIHB requests that the Committee double funding for the TBHG program to $80 million total, and that SAMHSA engage in Tribal consultation on restructuring the program to be formula-based with the option for Tribes to apply for funding under 638 self-governance authority.

Opioid Funding: NIHB was pleased to see a $50 million set aside for TOR grants and a $10 million set aside for medication-assisted treatment in fiscal year 2019. With AI/ANs experiencing the second highest overall opioid overdose rates, dedicated funding to Tribes for prevention and treatment is essential. In fiscal year 2018, 134 Tribes and Tribal organizations received TOR grant funding. NIHB requests that the Committee double the Tribal opioid funding set aside to 10 percent so that more Tribes can participate and existing grantees can expand the scope and delivery of services.

HIV and Minority AIDS Initiative Funding: Unlike Federal agencies such as SAMHSA and CDC, the IHS has historically not received direct appropriations under the Minority AIDS Initiative. Without direct funding, IHS, Tribal and urban Indian facilities (collectively I/T/U) have been forced to cobble together resources from disparate sources to provide HIV prevention services. Lack of direct resources for prevention have likely contributed to a 46 percent increase in HIV diagnoses among AI/ANs overall from 2010 to 2016. NIHB requests that the Committee enact a 5 percent Tribal set aside for Minority AIDS Initiative dollars under mental health, substance abuse prevention, and substance abuse treatment.

HEALTH RESOURCES AND SERVICES ADMINISTRATION

Health Workforce: As reported by IHS in its fiscal year 2020 Congressional Justification, the Indian health system currently has 1,330 vacancies for healthcare professionals including physicians, nurse practitioners, dentists, pharmacists, and physician assistants.[7] In fact, in a 2018 report released by the Government Accountability Office (GAO), provider vacancy rates across eight IHS Areas with substantial direct care responsibilities reached as high as 31 percent (GAO–18–580).[8] Without sufficient access to providers, the quality and accessibility of care in the Indian health system will not improve, and the health status of AI/ANs will remain lower than the general population. The fiscal year 2020 President's Budget proposed cutting funding for the National Health Service Corps (NHSC) by $15 million. Any cuts to NHSC funding would devastate the Indian health system, as I/T/U facilities retain the largest share of NHSC placements. NIHB requests that the Committee maintain its $15 million set aside in NHSC funding for placements within the Indian health system.

Health Centers: In addition to chronic provider shortages, the average age of I/T/U facilities is roughly 40 years, compared to an average age of roughly 10 years for health facilities nationwide.[9] In fact, research shows that an IHS facility built

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[7] fiscal year 2020 Justification of Estimates for Appropriations Committees: Indian Health Service.

[8] Government Accountability Office. (2018). Indian Health Service: Agency Faces Ongoing Challenges Filling Provider Vacancies.

[9] The 2016 Indian Health Service and Tribal Health Facilities' Needs Assessment Report to Congress. Retrieved from https://www.ihs.gov/newsroom/includes/themes/responsive2017/display__objects/documents/RepCong__2016/IHSRTC__on__FacilitiesNeedsAssessmentReport.pdf.

today would not be replaced for 400 years in the current budget environment.[10] IHS and Tribal health systems generally lack access to specialty care facilities, preventive health centers, behavioral and mental health clinics, and so forth. Despite the need, only 1.1 percent of patients served by HRSA's health center program were AI/AN in 2017. Direct access to health center funding can help improve Tribal health infrastructure by expanding funding for health services. As such, NIHB requests that the Committee enact a 3–4 percent set aside in Health Center funding for the I/T/U system.

Action for Dental Health Program: Nationwide, Tribal communities struggle with dental afflictions and disparities, as well as a severe oral health provider shortage. On average, Indian Country has just 1 dentist for every 2,800 people, which is half the number of dentists per capita nationwide. This shortage contributes to poorer oral health outcomes across all age groups in Tribal communities. In fact, 41 percent of AI/AN 2–5 year olds and 46 percent of AI/AN adults over the age of 65 have untreated tooth decay, compared to 10 percent and 19 percent of non-Natives in the same age groups.[11] As one of the many policy solutions to restore Indian Country's oral health, NIHB supports funding for the Action for Dental Health Program (42 U.S.C. 280k(c)), which includes direct funding to Tribes. NIHB recommends the Committee appropriate such sums as may be necessary—including a designated funding set aside for Tribes—for the implementation of the Action for Dental Health Program in fiscal year 2020.

Centers for Medicare and Medicaid Services: The Medicaid system is a critical lifeline in Tribal communities, accounting for roughly 13 percent of the overall IHS budget. Moving Medicaid to a block grant system, as proposed in the fiscal year 2020 President's Budget, would have major fiscal impacts on Tribal health reimbursements. We also urge Congress to ensure that AI/ANs are exempt from any mandatory work requirements under Medicaid, as they would impose additional and unmanageable burdens on an IHS budget that heavily relies on Medicaid resources to make up for funding shortfalls. NIHB urges the Committee to maintain the Medicaid program as is, and expand its reach and availability for AI/ANs.

Expansion of Self-Governance at HHS: For over a decade, Tribes have been advocating for expansion of self-governance authority to HHS programs outside of IHS. Self-governance represents efficiency, accountability and best practices in managing and operating Tribal programs and administering Federal funds at the local level. This proposal was deemed feasible by a Tribal/Federal HHS workgroup in 2011. Therefore, NIHB requests the Committee direct HHS to enter into pilot projects for self-governance in fiscal year 2020.

Thank you for the opportunity to submit testimony on the fiscal year 2020 HHS budget. We thank the Committee for its efforts towards prioritizing funding to Indian Country. Please do not hesitate to contact our offices directly if you have any questions or if you require additional information.

[This statement was submitted by Victoria Kitcheyan, Chairperson, National Indian Health Board.]

PREPARED STATEMENT OF THE NATIONAL INSTITUTE OF CHILD HEALTH AND HUMAN DEVELOPMENT

I am writing on behalf of the Friends of NICHD, a coalition of over 100 organizations representing patients, providers, scientists, and caregivers who are united in our support for ensuring the health and welfare of women, children, families, and people with disabilities through research funded by the Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD) and the National Institutes of Health (NIH). We urge the Subcommittee to provide NICHD with $1.6 billion in fiscal year 2020, an increase of $94 million over fiscal year 2019. We also respectfully ask the subcommittee to maintain its commitment to increasing funding for the National Institutes of Health (NIH) by providing $41.6 billion in fiscal year 2020, a $2.5 billion increase over fiscal year 2019.

We are pleased to support the extraordinary achievements of NICHD in meeting the objectives of its biomedical, social, and behavioral research mission, including research on child development before and after birth; women's health throughout the life cycle; maternal, child, and family health; learning and language develop-

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[10] Ibid.

[11] Phipps and Ricks, April 2015; Bruce A. Dye, Gina Thornton-Evans, Xianfen Li, and Timothy J. Iafolla, NCHS Data Brief No. 191, "Dental Caries Sealant Prevalence in Children and Adolescents in the United States, 2011–2012," March 2015, http://www.cdc. gov/nchs/data/databriefs/db191.pdf.

ment; reproductive biology; population health; and medical rehabilitation. With these necessary resources, NICHD can build upon the initiatives listed below to produce new insights and solutions to benefit women, children, and families in your districts and States.

Behavioral Health Research.—NICHD supports a range of research on child development and behavior and has made great progress developing sophisticated tools to measure children's cognitive, emotional, and social functioning. To build on these successes, we encourage more integrated behavioral and biobehavioral work on child developmental trajectories, across infancy, childhood, and adolescence, in both normative and at-risk environments, across diverse contexts (school, home, and community) and including underrepresented and vulnerable groups. More research is also needed on integrated behavioral health in primary care settings, including cost effectiveness comparisons, and the impact of behavioral interventions on mental health, physical health, and quality of life. Child health would also benefit from additional work on the role of technology to support optimal development in children, including those with disabilities, and increased access to and engagement with effective psychological and behavioral interventions for childhood conditions.

Poverty and Child Health.—Poverty can be especially detrimental in childhood and adolescence, leading to adverse impacts on physical health, mental health, social well-being, cognitive and emotional development, and the acquisition of motor and language skills. NICHD is in the unique position to examine the biological, psychological, social, cultural, and environmental factors that impact the developing child in high-poverty environments—including challenges due to chronic stress, neighborhood safety, school environments, family health status, education, job instability, unstable family structures, and substandard living conditions—and to evaluate interventions aimed at improving the developmental trajectories of these children.

Data on Pediatric Enrollment in NIH Trials.—NIH requires investigators to submit deidentified demographic data on study participants, including age at enrollment. It is important for NIH to analyze and report on this data to ensure that all populations, including children, benefit from research. NICHD should play a leading role in the implementation of this policy vis-à-vis age.

Infant and Childhood Health.—Through the Best Pharmaceuticals for Children Act (BPCA), NICHD funds the study of old, off-patent drugs important to children but inadequately studied in pediatric populations. We urge continued funding for this research and for training the next generation of pediatric clinical investigators. We also strongly support NICHD's ongoing research into the causes and prevention strategies for the major causes of death in infancy and childhood, including sudden unexpected infant death, accidents, and suicide.

Reproductive Sciences.—Research on the basic biological mechanisms of reproduction is a crucial foundation for all of the work of NICHD. Understanding reproductive biology and associated biological phenomena provides the foundation for innovative medical therapies and technologies and improves existing treatment options for gynecologic conditions. Often, this research focuses on serious conditions that are overlooked and underfunded, despite the fact that they impact many women. Future work could address infertility and the need for treatments for endometriosis, polycystic ovarian syndrome (PCOS) and uterine fibroids.

Pelvic Floor Disorders Network (PFDN).—Female pelvic floor disorders represent a major public health burden with high prevalence, impaired quality of life and substantial economic costs affecting 25 percent of American women. The PFDN conducts research to improve treatment of these painful gynecological conditions. Current research aims to improve female urinary incontinence outcome measures and ensure high quality outcomes.

PregSource.—NICHD's PregSource(tm) initiative allows pregnant women to track their health data from gestation to early infancy and access evidence-based information about healthy pregnancies. It will also allow researchers to utilize aggregated data and potentially recruit participants for clinical trials so that knowledge gaps can be eliminated and care for pregnant and post-partum women can be improved.

Task Force Specific to Research in Pregnant Women and Lactating Women (PRGLAC).—We urge Congress to continue its strong support of the NICHD-led PRGLAC Task Force, and to support the recommendations contained in the report to achieve broader inclusion of pregnant and lactating women in research and expansion of the workforce of clinicians and researchers with expertise in obstetric and lactation pharmacology and therapeutics, so that lifesaving treatments for this population are known to be safe and effective.

Human Development, Infancy Through Adulthood.—NICHD supports research on infant through adult development including how father-child relationships and coparenting positively impacts children's socio-emotional development and decreases behavior problems; children's adjustment after the birth of a sibling; pathways and outcomes associated with mothers' postseparation co-parenting relationships, with a particular focus on experiences of intimate partner violence and negative health outcomes; and the health and well-being across three generations of lesbians, gay men, and bisexuals.

Intellectual and Developmental Disabilities Research Centers (IDDRC).—The IDDRCs are a critical national resource for basic research into the genetic and biological basis of human brain development, greatly improving our understanding of the causes of developmental disabilities and contributing to the development and implementation of evidence-based practices by evaluating the effectiveness of biological, biochemical, and behavioral interventions. These centers have contributed to new treatments for genetic disorders through the study of intellectual and developmental disabilities, such as Everolimus for epilepsy in TSC. We must build on progress in the understanding and treating this class of disorders that affect so many. We urge resources and support for the IDDRCs for research infrastructure and expansion of cores to conduct basic and translational research to develop effective prevention, treatment, and intervention strategies for children and adults with developmental disabilities.

Maternal Mortality.—The Pregnancy and Perinatology Branch, through networks including the Maternal-Fetal Medicine Units (MFMU) Network, supports research to improve the health of women before, during and after pregnancy. Maternal mortality rates are at an unprecedented high in the United States and significant racial and ethnic disparities persist. Research to better understand the mechanisms of disparities, to include social determinants of health and genetic factors that adversely affect pregnancy outcomes, are vitally needed.

Preterm Birth.—NICHD supports a comprehensive research program on the causes, prevention, and treatment of preterm birth, the leading cause of infant mortality and intellectual and physical disabilities. Research shows the survival rate and neurological outcomes may be improving for very early preterm infants, but continued prioritization is needed through extramural preterm birth prevention research, the MFMU Network, the Neonatal Research Network, and intramural research program. Robust funding is needed for research to determine the complex interaction of behavioral, social, environmental, genetic, and biological influences on preterm birth with the goal of developing the interventions necessary to decrease prematurity.

Population Dynamics.—The NICHD Population Dynamics Branch supports research on how population change affects the health, development, and wellbeing of children and their families. Longitudinal surveys, such as the Fragile Families and Child Wellbeing Study, have demonstrated the role that family stability and parental involvement play in the long-term health and development of children, facilitating tremendous progress in the population sciences. NICHD also supports the Population Dynamics Centers Research Infrastructure Program, which supports research and research training in demographic or population research. These centers focus on research areas such as family demography and intergenerational relationships; education, work, and inequality; population health; and reproductive health.

[This statement was submitted by Joseph Laakso, Director of Science Policy, Endocrine Society, Friends of NICHD.]

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 requests $5 million to expand on the successes of the CDC CKD Initiative, sustained funding for Million Hearts, $2.165 billion for the National Institute of Diabetes, Digestive and Kidney Diseases, $32 million for HRSA Division of Transplantation (DoT) and increases necessary for the HRSA Bureau of Primary care to fight kidney disease. We also support a new funding item within HHS to support innovation in new renal replacement therapies through KidneyX.

ABOUT CKD

The National Kidney Foundation is encouraged by Secretary Azar's goal to reduce the burden of CKD, including an emphasis on awareness and early detection. New CDC data shows that CKD impacts 37 million American adults, while 1 in 3 adults (73 million) are at risk. Kidney disease can be detected through simple blood and urine tests yet often goes undetected until very advanced because it often has no symptoms (more than 90 percent of individuals with CKD are unaware they have it). Over 725,000 Americans have ESRD, 511,000 of whom receive dialysis at least 3 times per week to replace kidney function, and 215,000 Americans live with a kidney transplant. African Americans develop ESRD at a rate of 4:1 compared to Whites and Hispanic Americans develop it at a rate of 2:1 compared to Whites. Medicare spends nearly $114 billion annually on the care of people with CKD, including $71 billion for individuals with CKD who have not progressed to kidney failure.

The impact of CKD is further amplified as the disease burden is growing. A study published by researchers leading the CDC's surveillance program shows that over half of U.S. adults age 30–64 are likely to develop CKD. Many with CKD also have cardiovascular disease, bone disease and other chronic conditions, contributing to poor outcomes and increased health spending. CKD also is an independent risk predictor for heart attack and stroke. Intervention at the earliest stage is vital to improving outcomes, lowering healthcare costs, and improving patient experience, yet only 6 percent of patients with high blood pressure and 40 percent with diabetes (which are responsible for two-thirds of all cases of ESRD) receive testing for CKD. To improve awareness, early identification, and optimal treatment for kidney disease, the National Kidney Foundation calls on the Committee to sustain or increase funding for several agencies that are contributing substantially to these improvements.

CDC NCCDPHP

Nearly 15 years ago, the National Kidney Foundation worked with Congress to address the social and economic impact of kidney disease through the establishment of the CDC Chronic Kidney Disease Initiative. Results of the initiative include a heightened awareness of and information about CKD, a surveillance program, and educational resources for health professionals and the public. To enhance the fight against CKD, the National Kidney Foundation requests $5 million for the CKD program to establish and implement activities between national, State, and local public health networks and national partners to (1) develop strategies to identify and address gaps in CKD early detection and monitor progress; (2) support strategies to improve CKD early detection and treatment by primary care providers and; (3) facilitate the dissemination of information through State and local public health networks.

Another key to improving public health is addressing the link between kidney disease and cardiovascular disease. The National Kidney Foundation is collaborating with Million Hearts to improve assessment for CKD among those with hypertension. We urge Congress to continue support for Million Hearts in its goal to reduce heart attack and stroke by 1 million by 2022.

NIH NIDDK

NKF supports the Friends of NIDDK request of $2.165 billion for fiscal year 2020. Despite the impact of CKD on Medicare, NIH funding for kidney disease research is only about $600 million annually. America's scientists are at the cusp of many potential breakthroughs in improving our understanding of CKD and providing new therapies to delay and treat kidney diseases, which has the potential to provide cost savings to the government like that of no other chronic disease.

HRSA BUREAU OF PRIMARY CARE

The HRSA Bureau of Primary Care supports a national network of more than 9,800 health clinics for 1 in 13 people in underserved communities who otherwise would have inadequate or no access to care. Community Health Centers can serve as a first line of detection and care for people at risk and with CKD. NKF urges the Committee to increase funding for federally Qualified Community Health Centers to improve testing of CKD among those with diabetes and hypertension by including, in the Uniform Data System (UDS), laboratory values for estimated Glomerular Filtration Rate (eGFR) and urine albumin to creatinine ratio (ACR), which provide vital information on kidney function and the risk of progression and cardiovascular complications and CKD diagnosis. This would align with Healthy People 2020 objectives related to CKD detection and provide a critical data source for CKD surveillance.

HRSA DOT

The Division of Transplantation supports initiatives to increase the number of donor organs, including the National Living Donor Assistance program which helps offset living donors' expenses that are not reimbursed by insurance or other programs. We support the House Appropriations Committee request of $32 million to help ensure more ESRD patients have access to kidney transplantation, the therapy associated with the best outcomes. Despite an increase in the number of transplants, the wait list has remained relatively constant with nearly 115,000 people waiting for a life-saving organ, including 95,000 who are waiting for a kidney. Transplant experts agree the best opportunity to significantly increase the number of transplants is through living donation. However, barriers to living donation, including financial barriers so that individuals are not burdened with out of pocket expenses related to their donation, must be addressed. This funding also will help support a five-year pilot that will launch this Summer to test the impact covering lost wages for living donors has on increasing organ donation. We further request $1.5 million of the funding be used for social and behavioral interventions by community-based organizations to empower and educate kidney patients to seek a transplant from a living donor.

In October 2018 NKF issued the report of our Consensus Conference to Reduce Kidney Discards which brought transplant experts and government agencies together to address ways to remove barriers on the use of deceased donor kidneys that many believe are suitable for transplant. We have shared opportunities such as changes to transplant program metrics used by OPTN and changes to Medicare reimbursement for high-risk kidneys with the Administration. We also developed the Big Ask Big Give, a community-based program for patients, families and potential kidney donors designed to increase living kidney donation.

The National Kidney Foundation does not ask the Government to bear the responsibility CKD on its own and we have undertaken initiatives to drive forward improvements in kidney care. Our CKDIntercept initiative aims to transform Primary Care Practitioners' (PCP) detection and care of Americans with CKD by deploying evidence based clinical guidelines into primary care settings through education programs, symposia and practical implementation tools. Through this initiative, we have collaborated with the American Society for Clinical Pathology (ASCP) and the Nation's leading commercial laboratories and clinical laboratory societies to help remove barriers to CKD testing. A component of this new collaboration is a "Kidney Profile" which combines the blood and urine testes needed to calculate the eGFR, and assess kidney function and urine ACR, which assesses kidney damage. We also developed and submitted recommendations to CMMI for a patient-focused alternative payment model that will foster collaboration among PCPs and nephrologists to slow progression of CKD and ease transitions for those that progress to ESRD. The pilot will be practitioner-led and supported by a multidisciplinary healthcare team. In addition, it will provide Primary Care Practitioners and nephrologists with the resources they need to better care for people with CKD, while also ensuring they are accountable for measurable improvements in care. Practitioners will be rewarded for identifying kidney disease early so that the progression of the disease can be slowed resulting in better, long-term patient outcomes, such as a reduction in the number of patients dying early, requiring dialysis or needing kidney transplantation.

Thank you for your past support and your consideration of our requests for fiscal year 2020.

PREPARED STATEMENT OF THE NATIONAL LEAGUE FOR NURSING

As the oldest nursing organization in the United States, the NLN promotes excellence in nursing education to build a strong and diverse nursing workforce to advance the health of the Nation and the global community. The League represents more than 1,200 nursing schools, 40,000 members, and 25 regional constituent leagues. The NLN thanks the subcommittee for continued support for these programs. The Title VIII nursing workforce development programs ensure a strong nursing workforce able to meet the health demands of an aging population as well as the current opioid epidemic. The NLN urges the subcommittee to fund the Health Resources and Services Administration's (HRSA) Title VIII nursing workforce development programs at $266 million in fiscal year 2020.

NURSING EDUCATION AND WORKFORCE

The changing landscape of patient care, driven by greater consumer engagement, practice-driven technologies, and virtual healthcare, provides a unique context for teaching and learning. Teaching with and about emerging technology is the future of nursing education. Providing nursing care in a highly technological, connected work environment is the future of nursing practice (NLN 2015).

A high quality-nursing workforce equals high quality care for the Nation. With 4.8 million active, licensed vocational/practical nurses (LVNs/LPNs) and registered nurses (RNs), nurses are the primary professionals delivering quality healthcare in the Nation (NCSBN 2019). According to the Bureau of Labor Statistics (BLS), the RN workforce is projected to grow by 15 percent from 2016 to 2026, The BLS also estimates the LVN/LPN workforce will grow by 12 percent, the advanced practice registered nurses (APRNs) workforce will grow by 31 percent, and the need for nursing faculty will grow 24 percent during the same period (BLS 2017).

This increase is fueled by the opioid epidemic, demand for healthcare services for our aging population; for patients with various chronic conditions, such as arthritis, dementia, diabetes, and obesity; and for staffing facilities that provide long-term rehabilitation for stroke and head injury patients and those that treat people with Alzheimer's. In addition, because many older people prefer to be treated at home or in residential care facilities, nurses will be in demand in those settings.

DIVERSITY IN NURSING

Diversity and quality healthcare are inseparable. Diversity signifies that each individual is unique and recognizes individual differences—race, ethnicity, gender, sexual orientation and gender identity, socio-economic status, age, physical abilities, religious beliefs, political beliefs, or other attributes. It encourages self-awareness and respect for all persons, embracing and celebrating the richness of each individual. It also encompasses organizational, institutional, and system-wide behaviors in nursing, nursing education, and healthcare (NLN 2016).

There is a great need for diversity in the nurse workforce, student population, and faculty in order for nursing to achieve excellent care for all. Diversity in nursing is essential to a market-driven healthcare system that understands and addresses cultural challenges and social determinants of health in our rapidly changing population. Our Nation is enriched by cultural complexity—37 percent of our population identify as racial and ethnic minorities. Yet diversity eludes the nursing student and nurse educator populations. Minorities only constitute 27 percent of the student population and males only 14 percent of pre-licensure RN students (NLN 2016). Workforce diversity is especially needed where research indicates that factors such as societal biases and stereotyping, communication barriers, limited cultural sensitivity and competence, and system and organizational determinants contribute to healthcare inequities.

HRSA'S TITLE VIII NURSING WORKFORCE DEVELOPMENT PROGRAMS

For over 50 years, the Title VIII nursing workforce development programs have provided training for entry-level and advanced practice registered nurses (APRNs) to improve the access to, and quality of, healthcare in underserved communities. These programs provide students and schools of nursing with grants to strengthen education programs, including faculty recruitment and retention efforts, facility and equipment acquisition, clinical lab enhancements, loans, scholarships, and services that enable students to overcome obstacles to completing their nursing education programs. Many of the Title VIII grantees collaborate with health delivery sites in medically underserved communities, which is especially important as the opioid epidemic continues to ravage the country. Your ongoing support of HRSA's Title VIII nursing programs will help build the workforce needed to battle this epidemic.

Information from HRSA's Title VIII programs listed below provides a perspective on current Federal investments.

The *Advanced Nursing Education (ANE)* programs increase the number of qualified nurses in the primary care workforce by improving advanced nursing education through traineeships as well as curriculum and faculty development. The programs include a preference for supporting rural and underserved communities. In academic year 2017–2018, grantees of the ANE program trained 3,649 nursing students and produced 1,319 graduates. ANE grantees collaborated with 1,923 healthcare delivery sites to provide clinical and experiential training to students. Approximately 41 percent of these sites were located in medically underserved communities, and 63 percent were in primary care settings.

The *Nursing Workforce Diversity (NWD)* program increases nursing education opportunities for individuals from disadvantaged backgrounds, including racial and ethnic minorities who are underrepresented among registered nurses. The program supports disadvantaged students through student stipends and scholarships, and a variety of pre-entry preparation, advanced education preparation, and retention activities. In academic year 2017–2018, the NWD program supported 65 college-level degree programs as well as 164 training programs and activities designed to recruit and retain health professions students. These programs trained 6,549 students, including 2,886 students who graduated or completed their programs. In addition to providing support to students, NWD grantees partnered with 743 training sites during the academic year to provide 6,888 clinical training experiences to trainees across all programs. Approximately 48 percent of training sites were located in medically underserved communities and 33 percent were in primary care settings.

The *Nurse Education, Practice, Quality, and Retention Programs (NEPQR)* address national nursing needs and strengthen the capacity for basic nurse education and practice under three priority areas: Education, Practice and Retention. The NEPQR programs support the development, distribution and retention of a diverse, culturally competent health workforce that can adapt to the population's changing healthcare needs and provide the highest quality of care for all. Woven throughout the programs is the aim to increase the number of Bachelor of Science in Nursing (BSN) students exposed to enhanced curriculum and with meaningful clinical experience and training in medically underserved and rural communities, who will then be more likely to choose to work in these settings upon graduation. In academic year 2017–2018, the NEPQR programs focused on behavioral health integration in community-based primary care settings, RNs in primary care, and veteran RNs in community-based primary care settings.

The *Nurse Faculty Loan Program (NFLP)* seeks to increase the number of qualified nurse faculty by awarding funds to schools of nursing who in turn provide student loans to graduate-level nursing students who are interested to serve as faculty. Upon graduation, student borrowers are eligible to receive partial loan cancellation (up to 85 percent of the loan principal and interest over 4 years) in exchange for serving as full-time faculty at an accredited school of nursing. In academic year 2017–2018, 80 schools received new NFLP awards. Awardees supported 2,172 nursing students pursuing graduate level degrees as nurse faculty. The majority of students (84 percent) who received loans during the academic year were pursuing doctoral-level nursing degrees (e.g., PhD, DNP, DNSc/DNS, or EdD). By the end of the academic year, 800 trainees graduated, 94 percent of whom intended to teach nursing.

The *NURSE Corps Scholarship and Loan Repayment Program (NURSE Corps)* helps to improve the distribution of nurses by supporting nurses and nursing students committed to working in communities with inadequate access to care. In exchange for scholarships or educational loan repayment, NURSE Corps members fulfill their service obligation by working in Critical Shortage Facilities (CSFs) located in health professional shortage areas and medically underserved communities around the Nation, which include rural communities and other identified geographic areas with populations that lack access to primary care services. In fiscal year 2018, 54 percent of NURSE Corps loan repayment program participants extended their service commitment for an additional year and 89.7 percent of NURSE Corps participants were retained in service at a critical shortage facility for up to 2 years beyond the completion of their NURSE Corps service commitment. In addition, in fiscal year 2018, 97 percent of NURSE Corps scholarship program awardees are pursuing their baccalaureate degree or advanced practice degree. In fiscal year 2019, HRSA directed up to 20 percent of scholarship awards to NPs specializing in psychiatric-mental Health with the goal of leveraging HRSA funding to address the opioid crisis.

The NLN urges the subcommittee to fund the Title VIII nursing workforce development programs at $266 million in fiscal year 2020.

[This statement was submitted by G. Rumay Alexander, EdD, RN, FAAN, President, and Beverly Malone, PhD, RN, FAAN, Chief Executive Officer, National League for Nursing.]

PREPARED STATEMENT OF THE NATIONAL MINORITY CONSORTIA

The National Minority Consortia (NMC) submits this statement regarding the fiscal year 2022 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) To provide a much needed increase in funding to $495 million in fiscal year 2022 advance 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:

1. Provide fiscal year 2022 advance appropriation for CPB of $495 million, to continue a service that provides 97 percent of Americans, including those in

rural areas with free, unique local and national education resources that would otherwise not be available. CPB has been level-funded at $445 million a year for the past 10 years.

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. As the last locally-controlled media, the Federal investment in public media is essential to making these services available to everyone, everywhere, every day for free.

2. 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 House Report 115–862, pg. 163, 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 just under $6.8 million in discretionary funds from CPB per year, which equals to 1.5 percent of the CPB budget. A modest 10 percent increase to the NMC appropriation for a combined total of $7.5 million for the NMC will go a long way in supporting the continued development of diverse content and the support of filmmakers of color. It is essential that the images and stories on public media reflect the demographics of our country and that as a system we strive to bring a better understanding of our multicultural heritage.

ABOUT THE NATIONAL MINORITY CONSORTIA

The NMC is made up of five separate and distinct organizations that address the need for programing that reflects America's growing ethnic and cultural diversity. By developing and funding diverse content, training and mentoring the next generation of minority media makers, as well as brokering relationships between content creators and content aggregators, the NMC helps to ensure the future strength and relevance of Public Media content from and to diverse communities.

Black Public Media (BPM) was founded in 1979 as the National Black Programming Consortium fulfilling the need to develop films and television programs about the Black experience that took creative risks and addressed the needs of underserved audiences. Today, Black Public Media (BPM) fulfills its mission by providing seed money for projects and opportunities for distribution through PBS. For many filmmakers, including Spike Lee, Julie Dash, Stanley Nelson, Shola Lynch, and Byron Hurt, BPM became a beacon of support at the earliest stages of their careers. Today, after nearly 40 years of historic work, BPM continues to leverage its expertise by investing in innovative content creators and bringing to the public dynamic programs about the Black experience that provoke, educate, entertain and enlighten on and off the screen

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. CAAM funds, produces, distributes and exhibits works in film, television and digital media. CAAM's award-winning documentaries reach millions of viewers per year across the U.S. on public media. Recent films supported by CAAM include The Chinese Exclusion Act by Ric Burns and Li-Shin Yu, and the forthcoming Norman Mineta and His Legacy: An American Story by Dianne Fukami. CAAM also presents CAAMFest, the world's largest film festival for Asians and Asian American film.

Latino Public Broadcasting (LPB) is public's media largest Latino-focused content developer and funder providing programming to public television's nearly 360 stations and media platforms. In support of Latino filmmakers, LPB has awarded over 12 million dollars to media makers nationwide, and provided over 233 hours of national programming and digital content to PBS. LPB produces VOCES on PBS, the only public media series showcasing the rich diversity of the Latino American experience. Some productions include the landmark 3-part series Latino Americans, DOLORES, John Leguizamo's Road to Broadway, Willie Velasquez: Your Vote is Your Voice among many others.

Pacific Islanders in Communications (PIC) is to support, advance, and develop Pacific Island media content and talent that results in a deeper understanding of Pacific Island history, culture and contemporary challenges. PIC helps Pacific Islander stories reach national audiences through funding support for productions, training and education, broadcast services, and community engagement. Last year, PIC provided over 20 hours of content to public media, fostered 161 new partnerships, and awarded $260,000 to film projects. In 2019, PIC's documentaries Out of State and Eating Up Easter will air on the award-winning Independent Lens series on PBS. PIC's Emmy award-winning, six-part series Family Ingredients is gearing up for its third season on PBS. Pacific Heartbeat, PIC's seminal series which reached over 24 million households last year will begin its eighth season in May 2019.

Vision Maker Media (VMM) empowers and engages Native People to share stories. VMM serves Native producers and Indian country, in partnership with public television and radio, by working with Native media makers to develop, produce and distribute educational programs for public television and radio. This year, Vision Maker Media will deliver 20 documentaries to public broadcasting stations nationally. VVM 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, Indian organizations 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. VMM sees new opportunities to increase diversity in programming, production, audience and employment in the new media environment.

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 respectfully urge the Subcommittee to provide the following in fiscal year 2020:

—$454 million for the Agency for Healthcare Research and Quality (AHRQ)
—$8.445 billion for the Centers for Disease Control and Prevention (CDC) inclusive of $5 million for the National Neurological Conditions Surveillance Program authorized in the 21st Century Cures Act;
—$20 million for the Lifespan Respite Care Program;
—Robust support for Medicare and Medicaid and protection of Medicaid's current financing structure; and
—At least $41.6 billion for the National Institute of Health (NIH), including funds provided to the agency through the 21st Century Cures Act (Public Law 114–255) for targeted initiative;
—$150 million for the Patient Centered Outcomes Research Institute (PCORI); and
—An increase above fiscal year 2019's funding level of $12.9 billion for the Social Security Administration's administrative budget.

MS is an unpredictable, often disabling disease of the central nervous system that interrupts the flow of information within the brain, and between the brain and body. Symptoms range from numbness and tingling to blindness and paralysis. The progress, severity, and specific symptoms of MS in any one person cannot yet be predicted. Results of a new study from the Society confirm that nearly one million

Americans live with MS—more than double previous estimates. The Society addresses the challenges of each person affected by MS so that each person affected by MS can live their best life.

We believe that the President's fiscal year 2020 proposed budget request would set back research and hamper the ability of people with MS from receiving the coverage and services they need to live their best lives. The Society urges the Committee to reject these proposed cuts and instead, adequately fund research and programs and health coverage and services important to people with MS.

Agency for Healthcare Research and Quality (AHRQ).—AHRQ is a small agency that is revolutionizing the healthcare system based on healthcare costs and quality. It provides evidence for healthcare providers to use to make healthcare safer, higher quality, more accessible, equitable, and affordable. Reports like these are vital in ensuring that the healthcare community has science and evidence-based information to aid in consultations on treatment decisions. The Society does not endorse the President's call for AHRQ's consolidation but calls on Congress to provide $460 million for the Agency's base funding level in fiscal year 2020.

CENTERS FOR DISEASE CONTROL AND PREVENTION

The CDC is tasked with protecting public health and safety through the control and prevention of disease, injury, and disability. Unfortunately, budgetary cuts, insufficient and outdate data infrastructure and public health emergencies have limited its ability to collect data to track the incidence and prevalence of neurological diseases like MS. The 21st Century Cures Act authorized the creation of the National Neurological Conditions Surveillance System (NNCSS) within the Agency, and Congress provided funding for this important System last year. The Agency has set up demonstration projects in MS and Parkinson's disease in order to determine what information to collect and the best methods that can be expanded to use in other neurologic areas. Having strong and reliable prevalence data is critical to protecting the public health and funding new and novel research to treat neurologic conditions. The CDC has updated its website to reflect their implementation plan and timeline as well as a logic model that has their long-term strategy for the Surveillance system. We urge Congress to maintain funding for this important public health surveillance program and fund the CDC at $7.8 billion in fiscal year 2020—inclusive of $5 million for the NNCSS.

CENTERS FOR MEDICARE & MEDICAID SERVICES

Medicare.—It is estimated that approximately 30 percent of the MS population relies on Medicare as its primary insurer. Many of these individuals are under the age of 65 and receive the Medicare benefit because of their disability. The Society supports ensuring appropriate reimbursement levels for Medicare providers; maintaining access to diagnostics and durable medical equipment including power and manual complex rehabilitation technology and related accessories; protecting access to needed speech, physical and occupational therapy services; 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. Approximately 5–10 percent of people with MS have Medicaid 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.

LIFESPAN RESPITE CARE PROGRAM

The Lifespan Respite Care Program provides competitive grants to States to establish or enhance statewide lifespan respite programs that better coordinate and increase access to quality respite care. Approximately one quarter of individuals living with MS require long-term care services at some point during their lifetime. Often, a family member steps into the role of primary caregiver. Family caregivers allow the person living with MS to remain home for as long as possible and avoid premature admission to costlier institutional facilities. Family caregiving, while essential, can be draining and stressful. Respite offers professional short-term help to give caregivers a break from the stress of providing care and has been shown to provide family caregivers with the relief necessary to maintain their own health and bolster family stability. Much existing respite care has age eligibility requirements and importantly, the Lifespan Respite Care Program serves families regardless of special need or age. MS is typically diagnosed between the ages of 20 and 50, and Lifespan Respite programs are often the only open door to needed respite services. For these reasons, the Society asks that Congress provide $20 million for the Lifespan Respite Care Program in fiscal year 2020.

NATIONAL INSTITUTES OF HEALTH

The NIH is the Nation's premiere biomedical research institution and directly supports jobs in all 50 States. The NIH is a fundamental partner in the Society's mission to stop MS in its tracks, restore what has been lost, and end MS forever. To date, the Society has invested over $1 billion to MS research to date; but we rely on Congress to provide consistent and sustained investments to the agency to cultivate an environment that is optimal for scientific discovery. NIH continues to provide the basic research necessary to facilitate the development of novel therapies. In fact, the NIH has provided the basic research that has led to every MS treatment that is available today. Though much progress has been made in MS, there is still a great deal of unmet need, particularly those who live with progressive forms of the disease- now is not the time to decrease much needed Federal investment in NIH. The Society urges Congress to provide at least $41.6 billion for the NIH, including funds provided to the agency through the 21st Century Cures Act for targeted initiatives.

PATIENT-CENTERED OUTCOMES RESEARCH INSTITUTE

PCORI serves a vital role in ensuring that the public and private healthcare sectors have valid and trustworthy data on health outcomes, clinical effectiveness, and appropriateness of different medical treatments by both conducting research and evaluating existing studies. Its research addresses the need for real-world evidence and patient-focused outcomes data that will improve healthcare quality and help shift healthcare payment models toward value-based care. To date, PCORI has invested over $69 million in comparative effectiveness studies in MS. These studies will provide important evidence for the best ways to address questions surrounding what care approaches work best for whom, in what care settings. We recommend that Congress reauthorize PCORI to continue its important mission, fully fund its work in fiscal year 2020, and ensure that it has reliable and sustainable funding to continue its work in the future.

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 robust funding above the President's request of $12.773 billion for the Social Security Administration's administrative budget.

The National MS Society thanks the Committee for the opportunity to provide written testimony on our recommendations for fiscal year 2020 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 NURSE-LED CARE CONSORTIUM

On behalf of the National Nurse-Led Care Consortium (NNCC), I would like to thank the members of the Subcommittee for the opportunity to submit testimony regarding the importance of fully funding nursing workforce programs and how these programs impact nurses working in nurse-led models of care. Specifically, NNCC requests that $266 million be appropriated for the Nursing Workforce Development Programs (authorized under Title VIII of the Public Health Service Act [42 U.S.C. 296 et seq.]), and $170 million be appropriated for the National Institute of Nursing Research (NINR).

NNCC is a 501(c)(3) nonprofit public health organization that seeks to advance all forms of nurse-led care through policy development, technical assistance, and innovative programing. Nurse-led care exists at the intersection of multidisciplinary healthcare, where nurses have a transformative role as holistic caregivers, advocates, and leaders. Nurses have unique skills and insight to treat the whole person, serving as a critical connection between compassionate and evidence-based healthcare. Because of their education and community connections, advanced practice nurses are able to deliver high quality and cost-effective services to our most vulnerable populations.

Primarily, nurse practitioners run the health centers and practices NNCC represents. Nurse practitioners and other advanced practice nurses offer patient-centered care that is sensitive to patient needs and concerns. They work in all types of healthcare settings and specialties, such as retail health and acute care, but their services primarily revolve around primary care. NNCC assists these nurses by advocating for policy reforms that increase access to nurse-led care, designing community-based programs that address public health needs and offering expert technical assistance that enhances the sustainability of innovative nurse-led practice models.

As part of its mission, NNCC represents nonprofit, nurse-managed health clinics (sometimes called nurse-managed health centers or NMHCs). Section 254c-1a of the Public Health Service Act defines the term 'nurse-managed health clinic' as a "nurse-practice arrangement, managed by advanced practice nurses, that provides primary care or wellness services to underserved or vulnerable populations and that is associated with a school, college, university or department of nursing, federally qualified health center (FQHC), or independent nonprofit health or social services agency."[1] Recent estimates indicate that there are approximately 500 nurse-managed clinics nationwide, including birthing centers and school-based clinics. There are also approximately 2,500 nurse-led retail clinics based in pharmacies, grocery stores and other retail outlets around the country. Nurse-led models of care offer a full range of health services, including health promotion and disease prevention, to low-income, underinsured, and uninsured clients.

Because many nurse-led models of care are affiliated with schools of nursing, these clinics also help to build the capacity of the community-based healthcare workforce by acting as teaching and practice sites for nursing students and other health professionals. Each clinic associated with a nursing institution provides clinical placements for an average of 50 to 60 students a year.[2] These students include graduate and undergraduate nursing students, as well as medical, physician assistant, and social work students, among others.[3] Students participating in post-clinical focus groups express a high level of satisfaction with NMHC-based clinical placements, commenting that their experience in NMHCs highlighted the need to reduce healthcare disparities and respect patient diversity. A large percentage of the Federal funding for academically-affiliated NMHCs comes from the Title VIII Nurse Education, Practice, Quality, and Retention (NEPQR) program. Granting the requested appropriation will help ensure NMHCs and others forms of nurse-led care can continue taking advantage of the NEPQR program. Nurse-led clinical placements are particularly important to nursing education, because they offer nursing students hands-on experience working in underserved communities. These clinical placement sites also provide students with the opportunity to form relationships with nurse mentors working in leadership roles that can help build important business development and practice management skills often underemphasized in traditional nursing school curriculums.

One good example of the benefit of Title VIII funding to nurse-led clinics comes from the Vanderbilt University School of Nursing, which received a $999,101 grant from the NEPQR program in 2017. The two-year grant gives the Clinic at Mercury Courts, a nurse-managed primary care clinic located in one of Nashville's most economically depressed areas, the resources to add a psychiatric mental health nurse practitioner, social worker, and psychiatrist to its existing primary care team. The rate of substance abuse and mood disorders experienced by the community served by this clinic is more than four times the national average. The additional providers enable the clinic to comprehensively screen and treat both medical and behavioral health conditions, while addressing some of the problems associated with the deepening opioid crisis. In additional to its clinical services, the Mercury Courts clinic strengthens nursing education by offering clinical placements to nursing, medical, pharmacy, social work, and physician assistant students from a variety of disciplines and schools, including Lipscomb University, Tennessee State University,

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[1] Section 5208 of the Affordable Care Act.

[2] NNCC membership survey.

[3] NNCC membership survey.

Trevecca Nazarene University, University of Tennessee, and Vanderbilt's College of Arts and Science, Owen Graduate School of Management, Peabody College and Schools of Nursing, Divinity, Law and Medicine.

Title VIII funding is crucial to the success of the Mercury Court clinic, as well as hundreds of others like it across the Nation. For this reason, NNCC again requests that the Subcommittee appropriate $266 million to support Title VIII programs.

With regard to the National Institute of Nursing Research, NNCC believes that fully funding nursing research is vital to the recruitment and retention of qualified nursing faculty. According to the American Association of Colleges of Nursing's report on 2016–2017 Enrollment and Graduations in Baccalaureate and Graduate Programs in Nursing, U.S. nursing schools turned away 64,067 qualified applicants from baccalaureate and graduate nursing programs in 2016 due to an insufficient number of faculty, clinical sites, classroom space, clinical preceptors, and budget constraints.[4] Appropriating $170 million to the National Institute of Nursing Research will ensure that there are adequate research opportunities available to attract and retain experienced nursing faculty, while also improving nursing practice and patient outcomes. These enhanced research opportunities, in conjunction with the increase in clinical placement sites created by nurse-led practices funded through the requested Title VIII appropriation, constitute a two-pronged strategy for alleviating the nursing faculty shortage.

NNCC once again thanks the members of the Subcommittee for the opportunity to submit this testimony. If there any questions, please do not hesitate to contact me at cfattibene@nncc.us.

Sincerely.

[This statement was submitted by Cheryl L. Fattibene, MSN, MPH, CRNP, Chief Nurse Practitioner Officer, National Nurse-Led Care Consortium.]

PREPARED STATEMENT OF THE NATIONAL PANCREAS FOUNDATION

SUMMARY OF FISCAL YEAR 2020 APPROPRIATIONS RECOMMENDATIONS

- —The Foundation joins the broader research community in requesting that the National Institutes of Health (NIH) receive a funding increase of at least $2.5 billion for fiscal year 2020 to bring total agency funding up to a minimum of $41.6 billion annually.
  - —Please provide proportional increases for the various NIH Institutes and Centers, including the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) and the National Cancer Institute (NCI).
- —The Foundation joins the broader public health community in requesting that the Centers for Disease Control and Prevention (CDC) receive a funding increase of at least $500 million in discretionary resources to bring total agency funding up to a minimum of $7.8 billion annually.
  - —Please provide at least $500,000 in dedicated programmatic funding to initiate a public health program on pancreatitis at CDC's National Center for Chronic Disease Prevention and Health Promotion to facilitate critical surveillance, research, professional education, and public awareness activities.

Chairman Blunt, Ranking Member Murray, and distinguished Members of the Subcommittee, thank you for the opportunity to submit testimony on behalf of the National Pancreas Foundation (NPF) and the patient community that we serve. We deeply appreciate the investments in the National Institutes of Health (NIH) that have occurred over the past four fiscal years and the research advancements that additional resources have facilitated. For fiscal year 2020, we urge you to maintain this commitment to medical research and to similarly increase support for critical public health programs, most notably the Centers for Disease Control and Prevention (CDC). Thank you again.

ABOUT THE FOUNDATION

The National Pancreas Foundation is a patient-driven, non-profit organization that provides hope for those suffering from pancreatitis and pancreatic cancer by

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[4] American Association of Colleges of Nursing, Nursing Faculty Shortage Information Sheet, Available here: http://www.aacnnursing.org/News-Information/Fact-Sheets/Nursing-Faculty-Shortage.

funding cutting edge research, advocating for new and better therapies, and providing support and education for patients, caregivers, and healthcare professionals.

CONDITIONS OF THE PANCREAS

Pancreatitis can be acute of chronic. It is characterized by inflammation of the pancreas, and chronic pancreatitis does not heal or improve—it gets worse over time and leads to permanent damage. Chronic pancreatitis eventually impairs a patient's ability to digest food and make pancreatic hormones. Chronic pancreatitis can strike at any age, but often develops in patients between the ages of 30 and 40, and is more common in men than women. The annual incidence rate is 5 -12 per 100,000 and the prevalence is 50 per 100,000. Pancreatitis can be managed with proper information and healthy practices.

Pancreatic cancer is currently the third leading cause of cancer deaths in the United States. One of the major challenges associated with pancreatic cancer is that the condition often goes undetected for a long period of time because signs and symptoms seldom occur until advanced stages. By the time symptoms occur, cancer cells are likely to have spread (metastasized) to other parts of the body, often preventing surgical removal of tumors. Research indicates an emerging link between pancreatitis and the onset of pancreatic cancer.

NIH RESEARCH: PROGRESS AND OPPORTUNITIES

NIDDK has been a leader on pancreatitis research while NCI has facilitated key breakthroughs for pancreatic cancer. More work needs to be done though as translation and clinical research are necessary to ensure innovative treatment options and diagnostic tools can be deployed to the benefit of affected patients.

In this regard, NIDDK recently hosted an effort with the community to capitalize on progress for pancreatitis and ensure promising ideas move into the FDA pipeline for review. The need remains great as pancreatitis patients currently have extremely limited treatment options despite the severity of the illness.

Moreover, the Cancer Moonshot has been extremely meaningful for scientific efforts focused on pancreatic cancer. Similar to pancreatitis though, treatment options remain extremely limited despite the severity of the disease. In fact, due to improvements in other areas and an overall lack of progress in outcomes, pancreatic cancer is now the third leading cause of cancer deaths in America.

Over recent years, key Committee Recommendations have been included that have moved key pancreas research projects forward and it is our hope that the Subcommittee will continue to demonstrate an interest in this area during the fiscal year 2020 process.

CDC PUBLIC HEALTH OPPORTUNITIES

The National Center for Chronic Disease Prevention and Health Promotion coordinates line-item public health programs on a variety of conditions. Recently, CDC has limited their public health activities almost exclusively to these named efforts. While these programs have been highly successful for the conditions they represent, there is a tremendous public health need to launch a similar program for pancreatitis.

A lack of adequate professional and public information about pancreatitis leads to a suboptimal situation where patients are not effectively managing the condition and as it progresses inappropriate interventions occur, most notably unnecessary surgery to remove the pancreas. The CDC can fill key knowledge gap with a pancreatitis program to disseminate best practices to the professional community and make sure public health messages reach at-risk individuals. Pancreatitis can often be managed if the proper information is available, which can prevent the progression of disease, including the onset of pancreatic cancer.

A modest investment of $500,000 for a pancreatitis program would pay dividends in terms of reduced patient suffering and reduced costs to the healthcare system.

COMMUNITY STORY: BY JANE MACKE—LOUISIANA

Seeing your child writhing in pain and not being able to do anything able is a horrible feeling. Not being able to insure that your child gets the medical attention needed is just as bad. As a parent with a child with pancreatitis, I endured both due to the lack of knowledge about pediatric pancreatitis by medical professionals. My child endured the worst, being the patient of physicians and medical professionals who were not sure how to treat pancreatitis. It took several years of research, consults, and traveling to see physicians in other States to finally get the help needed for my child.

My son, Cameron, was first diagnosed with pancreatitis at 8 years of age, in October 2006. Cameron had been experiencing flu-like symptoms for several days, e.g. nausea, vomiting and diarrhea. His symptoms were getting worse, so I took him to an urgent care facility. The physician on duty stated that Cameron was dehydrated, had appendicitis and needed to go a hospital. At that time, 10 months after Hurricane Katrina, the only pediatric surgeon was at Children's Hospital in New Orleans. We immediately left the urgent care facility and went to the Children's Hospital. Diagnostic tests were run while Cameron was in the emergency room. The pediatric surgeon came in and told us that the tests revealed that Cameron did not have appendicitis, but he had abnormal fluid in the abdominal area. A pediatric gastroenterologist was brought in to care for Cameron. He diagnosed Cameron with pancreatitis. After ruling out trauma, the physician thought it may have been a case of idiopathic acute pancreatitis. However, Cameron had another severe pancreatic attack 2 months later. After the second episode, the pediatric gastroenterologist ordered genetic testing. Cameron was found to have two SPINK 1 mutations. Cameron was not initially tested for cystic fibrosis, but subsequent testing in 2015 revealed that he also has a CFTR mutation.

Being a research attorney, I did what did best—researching the disease of pancreatitis. I found the National Pancreas Foundation website, which included medical journal articles by Dr. David Whitcomb and Dr. Mark Lowe. I contacted Dr. Lowe, who agreed to evaluate and consult about my child. We went to Pittsburgh in April 2007 for the consult. I maintained contact with Dr. Lowe and often sent emails to him concerning Cameron's care when Cameron was hospitalized in New Orleans because the physicians in New Orleans were unsure about how to care for Cameron. There were times when some of the physicians did not believe Cameron had heredity or familial pancreatitis, even though the test results were in his chart. There were pediatric hospitalists and ED physicians who did not believe a child could have pancreatitis and/or suffer the pain they stated that they had. I had to learn to be an advocate for my child and stand my ground with medical professionals. I had to learn more about the disease of pancreatitis than some of the medical professionals even had an interest in learning.

From 2006 through 2007, Cameron had numerous minor flares and was hospitalized only three times during that period. Cameron's symptoms would mainly consist of abdominal and back pain. Sometimes, he would experience nausea. However, in February 2008, the severity of the attacks increased. From February 2008 through October 2008, Cameron was hospitalized five times for at least a week each time. During the second hospitalization in October 2008, a CT scan showed that Cameron had stones in his pancreatic duct. An adult gastroenterologist and pancreas specialist from Ochsner Hospital was called in for a consult. The physician performed an emergency ERCP and discovered Cameron had pancreatic divisum. From December 2008 through February 2015, Cameron was hospitalized at least twelve times and underwent eight ERCPs to remove stones and place stents in the pancreatic duct. We had to travel to San Antonio in 2011 for two of the ERCPS because there were no physicians in New Orleans at that time that would perform an ERCP on a child.

In February 2015, Cameron's gastroenterologist referred him to the University of Minnesota Masonic Children's Hospital for a total pancreatectomy with auto islet transplant. Cameron underwent the TP–AIT in June 2015, the summer before his senior year of high school. In addition to the physical aspects of pancreatitis, Cameron suffered with depression and PTSD. By February 2015, Cameron had endured 36 known episodes of pancreatitis, 21 hospitalizations and 9 ERCPs. As a parent, I had learned more about a disease than I have never heard of 10 years prior. I read medical journal articles and learned how to read medical charts and test results. I kept a diary of all Cameron's hospitalizations and tests results, which I took with me to the hospital each time Cameron was hospitalized. There was always the possibility that the physicians were not knowledgeable and/or would not review Cameron's chart. (And it did happen on a few occasions).

This disease causes havoc not only on child's physical well-being, but also on his emotional and social well-being. The numerous hospitalizations and the pain endured diminishes the child's ability to attend school and socialize with friends and family. Parents who care for their child also miss work and employment opportunities. The stress and time taken to care for one child can affect other children and family members. Parents, as well as the child who is sick, and other family members need support from family, friends and their community. The cost of this disease is not just financial. It affects every part of person's life, and every part of the family's life.

[This statement was submitted by Matt Alsante, Executive Director, National Pancreas Foundation.]

PREPARED STATEMENT OF THE NATIONAL PTA AND THE PACER CENTER

National PTA and the PACER Center would like to thank the 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 2020 funding. National PTA and the PACER Center, two of the Nation's leading family engagement organizations, respectfully request that the Subcommittee include $15 million for the Statewide Family Engagement Centers (SFECs) grant program in fiscal year 2020 funding legislation. National PTA is the oldest and largest volunteer child advocacy association in the United States with 3.5 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.

In addition to our support of additional resources for the SFEC program, we recognize that non-defense discretionary (NDD) funding for fiscal year 2020 will be cut by $55 billion if caps under the Budget Control Act are not raised. While strongly advocating for this increase, we also urge Congress to first reach a new budget agreement to avert these cuts and increase NDD funding levels over fiscal year 2019. This budget deal and an increase in the spending caps is vital to being able to provide $15 million for this program.

Our organizations request $15 million in funding for the U.S. Department of Education's SFECs grant program for fiscal year 2020. This investment comes after Congress provided $10 million in fiscal year 2019 and the House (L–HHS–ED) Subcommitte approved $15 milllion for this program in their fiscal year 2020 bill, an increase of $5 million over fiscal year 2019. To date, families and educators in 13 States have access to the services these centers provide and are beginning to benefit from the impact of their work on schools, families, and most importantly children. An increase of $5 million over fiscal year 2019 would allow additional States to be awarded grants, which depending on grant size, could increase the total number of States to nearly 20. We very much appreciate the Subcommittee's leadership in providing funding in fiscal year 2019 and ask you to provide this vital increase for fiscal year 2020.

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] Additonal research has shown that a school's approach to family engagement is equally as important in predicting its improvement as having a great principal, investing in strong teachers and curriculum, and using student-centered approaches to discipline.[3]

An fiscal year 2020 $15 million investment in the SFECs program will allow expansion of the number of States receiving grants and further build capacity for States and school districts to systematically embed family engagement policies and practices in their education plans. With this appropriation, centers will provide much needed professional development for educators and school leaders to strengthen school-family partnerships and parent-teacher relationships. This additional investment will also provide direct services to families to give them the tools to effectively work with their child's school to improve their child's academic outcomes and overall well-being.

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[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.

[3] Bryk, et al. (2010). Organizing Schools for Improvement: Lessons from Chicago. Chicago: University of Chicago Press.

School leaders and parents need the resources that SFECs can provide to engage parents as stakeholders and effectively implement ESSA as Congress intended. We are encouraged by the significant increase provideded in the House (L–HHS–ED) bill and urge the Senate Subcommittee to also include $15 million for the Statewide Family Engagement Centers program in the fiscal year 2020 Senate L–HHS–ED appropriations bill.

We appreciate your consideration of this request and are happy to follow up on any questions you may have.

[This statement was submitted by Nathan R. Monell, CAE, Executive Director, National PTA, and Paula F. Goldberg, Executive Director, PACER Center.]

PREPARED STATEMENT OF THE NATIONAL RESPITE COALITION

Mr. Chairman, I am Jill Kagan, Chair, National Respite Coalition (NRC), which is a network of state respite coalitions, respite providers, family caregivers, and national, State and local organizations that support respite. We are requesting that the Subcommittee include $20 million for the Lifespan Respite Care Program administered by the Administration for Community Living, Department of Health and Human Services, in the fiscal year 2020 Labor, HHS, and Education Appropriations bill. This modest increase will enable:

—State replication of Lifespan Respite best practices to allow family caregivers, regardless of the care recipient's age or disability, to have access to affordable respite.

—Improvement in respite quality and expansion of respite capacity; and

—Greater consumer direction by providing family caregivers with training and information on how to find, use and pay for both formal and informal respite services.

Respite Care Saves Money and Benefits Families

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 U.S. 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). Additional research has corroborated the role that respite may play in reducing or delaying facility-based placements (Gresham, 2018; Avison, et al., 2018). Respite may reduce administrative burdens and improve maternal employment (Caldwell, 2007), strengthen marriages (Harper, 2013), and significantly reduce caregiver depression, stress and burden levels linked to caregiver health (Broady and Aggar, 2017; Lopez-Hartmann, et al., 2012; Zarit, et al., 2014). 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 jumped 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). The University of NE Medical Center conducted a survey of caregivers receiving respite through the NE Lifespan Respite Program and found that 36 percent of family caregivers reported not having enough money at the end of the month to make ends meet, but families overall reported a better financial situation when receiving respite (Johnson, J., et al., 2018).

Who Needs Respite?

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). 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, 2015). In addition, the 2017 National Survey of Children's Health found that 13.3 million children under age 18 have special healthcare needs (Child and Adolescent Health Measurement Initiative, 2019).

National, State and local surveys have shown respite to be among the most frequently requested services by family caregivers (Anderson, L, et al., 2018; Maryland Caregivers Support Coordinating Council, 2015). Yet, 85 percent of family caregivers of adults are not receiving respite services at all (NAC, 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 more appropriate community-based respite care should be more widely available to military caregivers (Ramchand, et al., 2014).

Respite Barriers and the Effect on Family Caregivers

While most families want to care for family members at home, 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. In a survey of more than 3000 caregivers of individuals with intellectual and developmental disabilities (ID/DD), nine in ten reported that they were stressed. Nearly half (49 percent) reported that finding time to meet their personal needs was a major problem. Yet, more than half of the caregivers of individuals with ID (52 percent), Autism Spectrum Disorder (ASD) (56 percent) or ID and ASD (60 percent) reported that it was difficult or very difficult to find respite care (Anderson, L., et al., 2018). 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 family caregivers, found that nearly half of the caregivers had unmet needs for mental healthcare and most of these, 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. Moreover, a critically short supply of well-trained respite providers may prohibit a family from making use of a service they so desperately need.

Lifespan Respite Care Program

The Lifespan Respite Care Program, designed to address these barriers to respite quality, affordability and accessibility, is a competitive grant program administered by the Administration for Community Living (ACL) in its Center for Integrated Programs. The premise behind the program is both care relief and cost effectiveness. Lifespan Respite provides funding to States to expand and enhance local respite services across the country, coordinate community-based respite services to reduce duplication and fragmentation, improve coordination with other community resources, and improve respite access and quality. Under the program, States are required to establish statewide 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. 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 are eligible.

To date, 37 States and the District of Columbia have received basic grants to build coordinated systems of community-based respite services. Many of these

States have also received follow on grants to provide or expand direct services, to address the direct care worker shortage by recruiting and training respite workers, to integrate respite into statewide long-term services and support and No Wrong Door systems, to recruit and train respite workers, 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, CO, DE, IL, MD, MT, NE, NV, NC, OK, RI, SC, TN, VA, WI and WA, have successfully used consumer-directed respite vouchers for serving underserved populations often not eligible for other public programs, including individuals with traumatic brain injury, MS or ALS, adults with intellectual or developmental disabilities (I/DD), children with autism or special medical needs, rural caregivers or those on waiting lists for services.

—States are reporting positive family caregiver outcomes. AL’s respite voucher program found a substantial decrease in the percentage of caregivers reporting how often they felt overwhelmed with daily routines after receiving respite. Caregivers in NE’s Lifespan Respite program reported significant decreases in stress levels, fewer physical and emotional health issues, and reductions in anger and anxiety.

—Innovative and sustainable respite services funded in CO, MA, NC, NY, OH, PA, and SC through mini-grants to community-based agencies, have documented caregiver benefits.

—AL, IL, MD, and NE offer emergency respite support and AL, AR, CO, NE, NY, PA, RI, SC and TN are providing new volunteer or faith-based respite services.

—Respite provider recruitment and training are priorities in AR, CO, NE, NV, NY, SC, VA, and WI.

Partnerships between State agencies are changing the landscape. Lifespan Respite WA, housed in WA’s Aging & Long-Term Support Administration, partnered with WA’s Children with Special Health Care Needs Program to provide respite vouchers to families across ages and disabilities. The WA Lifespan Respite grantee also partnered with Tribal entities to provide respite to kinship caregivers. The OK Lifespan Respite program partnered with the State’s Transit Administration to develop mobile respite to serve isolated rural areas of the State. States are building respite registries and “no wrong door systems” in partnership with Aging and Disability Resource Centers/No Wrong Door systems to help family caregivers access respite and funding sources. Funding must be increased to help sustain these innovative State efforts and expand grants to new States. States are developing long-term sustainability plans, but without Federal support, many of the grantees will lose funding.

Funding Levels

Congress initially passed the Lifespan Respite Care Program in a bipartisan manner and the program maintains strong, bipartisan support in Congress. The program was authorized at $50 million/year based on the magnitude of our Nation’s family caregivers’ needs, but Congress first appropriated only $2.5 million from fiscal year 2009 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 provided first-time awards to Maryland and Mississippi. For fiscal year 2017, the program was once again funded at $3.36, permitting funding of two new States (ND and SD) and enabling 12 grantees to continue their ground-breaking work to serve more families. An increase in funding to $4.1 million in fiscal year 2018 and fiscal year 2019 allowed an additional four States to implement their Lifespan Respite grant activities. In April, the Lifespan Respite Care Reauthorization Act of 2019 was introduced in the House by Reps. Jim Langevin (D–RI) and Rep. Cathy McMorris Rodgers (R–WA) in the Senate by Senators Susan Collins (R–ME) and Tammy Baldwin (D–WI). With continued bipartisan support, the bill authorizes $200 million over 5 years.

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, funds respite start-up, provider recruitment and training, and coordination, and addresses accessibility and affordability issues for families regardless of the care recipient's age or disability. We urge you to include $20 million in the fiscal year 2020 Labor, HHS, and Education appropriations bill. This is the amount authorized in the newly introduced Lifespan Respite Reauthorization bill. Families will be able to keep loved ones at home, saving Medicaid and other Federal programs billions of dollars.

For more information, please contact Jill Kagan, National Respite Coalition at jkagan@archrespite.org. References available on request.

[This statement was submitted by Jill Kagan, Chair, National Respite Coalition.]

PREPARED STATEMENT OF THE NEPHCURE KIDNEY INTERNATIONAL

SUMMARY OF RECOMMENDATIONS FOR FISCAL YEAR 2020

—Provide $41.6 billion for the National Institutes of Health (NIH)

—Provide a proportional increase for the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) and the National Institute on Minority Health and Health Disparities (NIMHD) and support the expansion of the FSGS/NS research portfolio at NIDDK and NIMHD by funding more research into primary glomerular disease.

Chairman Blunt and Ranking Member Murray, thank you for the opportunity to present the views of NephCure Kidney International regarding research on idiopathic focal segmental glomerulosclerosis (FSGS) and primary nephrotic syndrome (NS). NephCure is the only non-profit organization exclusively devoted to fighting FSGS and the NS disease group. Driven by a panel of respected medical experts and a dedicated band of patients and families, NephCure works tirelessly to support kidney disease research and awareness.

NS is a collection of signs and symptoms caused by diseases that attack the kidney's filtering system. These diseases include FSGS, Minimal Change Disease and Membranous Nephropathy. When affected, the kidney filters leak protein from the blood into the urine and often cause kidney failure, which requires dialysis or kidney transplantation. According to a Harvard University report, 73,000 people in the United States have lost their kidneys as a result of FSGS. Unfortunately, the causes of FSGS and other filter diseases are poorly understood.

FSGS is the second leading cause of NS and is especially difficult to treat. There is no known cure for FSGS and current treatments are difficult for patients to endure. These treatments include the use of steroids and other dangerous substances which lower the immune system and contribute to severe bacterial infections, high blood pressure and other problems in patients, particularly child patients. In addition, children with NS often experience growth retardation and heart disease. Finally, NS that is caused by FSGS, MCD or MN is idiopathic and can often reoccur, even after a kidney transplant.

FSGS disproportionately affects minority populations and is five times more prevalent in the African American community. In a groundbreaking study funded by NIH, researchers found that FSGS is associated with two APOL1 gene variants. These variants developed as an evolutionary response to African sleeping sickness and are common in the African American patient population with FSGS/NS. Researchers continue to study the pathogenesis of these variants.

FSGS has a large social impact in the United States. FSGS leads to end-stage renal disease (ESRD) which is one of the most costly chronic diseases to manage. In 2008, the Medicare program alone spent $26.8 billion, 7.9 percent of its entire budget, on ESRD. In 2005, FSGS accounted for 12 percent of ESRD cases in the U.S., at an annual cost of $3 billion. It is estimated that there are currently approximately 20,000 Americans living with ESRD due to FSGS.

Research on FSGS could achieve tremendous savings in Federal healthcare costs and reduce health status disparities.

ENCOURAGE FSGS/NS RESEARCH AT NIH

There is no known cause or cure for FSGS and scientists tell us that much more research needs to be done on the basic science behind FSGS/NS. More research could lead to fewer patients undergoing ESRD and tremendous savings in healthcare costs in the United States. NephCure works closely with NIH and has partnered with NIH on two large studies that will advance the pace of clinical research and support precision medicine. These studies are the Nephrotic Syndrome Study Network and the Cure Glomerulonephropathy Network.

With collaboration from other Institutes and Centers, ORDR established the Rare Disease Clinical Research Network. This network provided an opportunity for NephCure Kidney International, the University of Michigan, and other university research health centers to come together to form the Nephrotic Syndrome Study Network (NEPTUNE). Now in its second 5-year funding cycle, NEPTUNE has recruited over 450 NS research participants, and has supported pilot and ancillary studies utilizing the NEPTUNE data resources. NephCure urges the subcommittee to continue its support for RDCRN and NEPTUNE, which has tremendous potential to facilitate advancements in NS and FSGS research.

NIDDK houses the Cure Glomerulonephropathy Network (Cure GN), a multicenter five-year cohort study of glomerular disease patients. Participants will be followed longitudinally to better understand the causes of disease, response to therapy, and disease progression, with the ultimate objective to cure glomerulonephropathy. NephCure recommends that the subcommittee continues to support the work that the Cure Glomeruloneuropathy [CureGN] initiative has accomplished towards further understanding rare forms of kidney diseases. It is estimated that annually there are 20 new cases of ESRD per million African Americans due to FSGS, and 5 new cases per million Caucasians. This disparity is largely due to variants of the APOL1 gene. Unfortunately, the incidence of FSGS is rising and there are no known strategies to prevent or treat kidney disease in individuals with the APOL1 genotype. NIMHD began supporting research on the APOL1 gene in fiscal year 2013. Due to the disproportionate burden of FSGS on minority populations, it remains appropriate for NIMHD to continue to advance this research. NephCure asks the subcommittee to recognize the work that NIMHD and NIDDK are doing to address the connection between the APOL1 gene and the onset of FSGS and encourage NIMHD to work with community stakeholders to identify areas of collaboration.

As a result of the important research done through NIH we have been able to work with FDA to establish new endpoints for clinical trial leading to more trials than ever before. This has led to the creation of the Kidney Health Gateway Clinical that will connect patients with breakthrough clinical trials and access top Nephrotic Syndrome doctors all in one place. These crucial trials will hopefully lead to more treatment options for our patients.

PATIENT PERSPECTIVE

My name is Kimberly Queen and I was diagnosed with Focal Segmental Glomerulosclerosis (FSGS) in 2012 at the age of 25. At that time, I was fulfilling my passion teaching Georgia State Pre-k when I received the news; It was only my third-year teaching. After only 2 months of being diagnosed and being prescribed 60mg of Prednisone, I went into septic shock. Thankfully I was surrounded by amazing doctors who saved my life. It was then that I realized it was time to fight this disease. However, just as I was starting my fight, my kidneys failed in the first 9 months. I am forever grateful to my brother who donated his kidney to me on November 7, 2014, but with FSGS there is always a chance of reoccurrence, which I saw firsthand shortly after when I began spilling protein. During the two weeks I spent in the hospital, we started putting together a game plan for how to put this awful disease into remission. I began daily plasmapheresis along with taking a blood pressure medication. We saw a little change but not enough. It's now been 3 years since my reoccurrence. In that time, I have done over three hundred plasmapheresis treatments, experimented with different dosages of Prednisone, tried different blood pressure medications, started using Acthar Gel and started Rituximab. I have attained partial remission using the Acthar Gel, and we are hoping to reach full remission with the Rituximab. More research is needed with this disease so that myself, and others do not feel like "test subjects" trying different medications and so there can be a higher success rate. I would love to be able to live my life not focused around doctor appointments, treatments and long infusions. Luckily, I am surrounded by a family who understand and show FSGS has impacted my life, as well as friends who support me and encourage me to stay strong daily fighting a disease with no cure.

Thank you for the opportunity to present the views of the FSGS/NS community.

[This statement was submitted by Irving Smokler, PH.D., President and Founder, NephCure Kidney International.]

PREPARED STATEMENT OF THE NEUROFIBROMATOSIS NETWORK

Thank you for the opportunity to submit testimony to the Subcommittee on the importance of funding for the National Institutes of Health (NIH), and specifically for continued research on Neurofibromatosis (NF), a genetic disorder closely linked to many common diseases widespread among the American population. My name is Kim Bischoff and I am the Executive Director of the Neurofibromatosis (NF) Network, a national organization of NF advocacy groups. We respectfully request that you include the following report language on NF research at the National Institutes of Health within the Office of the Director account in the fiscal year 2020 Labor, Health and Human Services, Education Appropriations bill.

Neurofibromatosis [NF].—The Committee supports efforts to increase funding and resources for NF research and treatment at multiple Institutes, including NCI, NINDS, NIDCD, NHLBI, NICHD, NIMH, NCATS, and NEI. Children and adults with NF are at significant risk for the development of many forms of cancer, as well as deafness, blindness, developmental delays and autism; the Committee encourages NCI to increase its NF research portfolio in fundamental laboratory science, patient-directed research, and clinical trials focused on NF-associated benign and malignant cancers. The Committee also encourages NCI to support clinical and preclinical trials consortia. Because NF can cause blindness, pain, and hearing loss, the Committee urges NINDS to continue to aggressively fund fundamental basic science research on NF relevant to restoring normal nerve function. Based on emerging findings from numerous researchers worldwide demonstrating that children with NF are at significant risk for autism, learning disabilities, motor delays, and attention deficits, the Committee encourages NINDS, NIMH, and NICHD to increase their investments in laboratory-based and patient-directed research investigations in these areas. Since NF2 accounts for approximately 5 percent of genetic forms of deafness, the Committee encourages NIDCD to expand its investment in NF2-related research. NF1 can cause vision loss due to optic gliomas. The Committee encourages NEI to expand its investment in NF1-focused research on optic gliomas and vision restoration.

On behalf of the Neurofibromatosis (NF) Network, I speak on behalf of the over 100,000 Americans who suffer from NF as well as 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.

CANCER

NF can cause a variety of tumors to grow, which includes tumors in the brain, spinal cord and nerves. NF affects the RAS pathway which is implicated in 70 percent of all human cancers. Some of these tumor types are benign and some are malignant, hard to treat and often fatal. Previous studies have found a high incidence of intracranial glioblastomas and malignant peripheral nerve sheath tumors (MPNSTs), as well as a six-fold incidents of breast cancer compared to the general population. One of these tumor types, malignant peripheral nerve sheath tumor (MPNST), is a very aggressive, hard to treat and often fatal cancer. MPNSTs are fast growing, and because the cells change as the tumor grows, they often become resistant to individual drugs. Clinical trials are underway to identify a drug treatment that can be widely used in MPNSTs and other hard-to-treat tumors.

The enormous promise of NF research, and its potential to benefit over 175 million Americans who suffer from diseases and conditions linked to NF, has gained increased recognition from Congress and the NIH. This is evidenced by the fact that numerous institutes are currently supporting NF research, and NIH's total NF research portfolio has increased from $3 million in fiscal year 1990 to an estimated $31 million in fiscal year 2019. Given the potential offered by NF research for progress against a range of diseases, we are hopeful that the NIH will continue to build on the successes of this program by funding this promising research and thereby continuing the enormous return on the taxpayers' investment.

We appreciate the Subcommittee's strong support for the National Institutes of Health and will continue to work with you to ensure that opportunities for major advances in NF research at the NIH are aggressively pursued. Thank you.

PREPARED STATEMENT OF NEW LEADERS

Thank you for the opportunity to provide testimony regarding the fiscal year 2020 Labor, Health and Human Services, Education, and Related Agencies Appropriations bill.

New Leaders is a national nonprofit organization dedicated to ensuring high academic achievement for all children, especially students in poverty and students of color, by developing transformational school leaders and advancing the policies and practices that allow great leaders to succeed. Since 2000, we have trained 3,900 outstanding school leaders who annually reach nearly half a million students in partnership with more than 30 districts and 150 charter schools. Moreover, our leaders overwhelmingly work on behalf of historically underserved students: 78 percent of students served are low-income and 87 percent are children of color. In addition, our programs are evidence-based. Multiple independent studies have found that students who attend New Leader schools outperform their peers by statistically significant margins specifically because of the strong leadership of their New Leader principal.[1] And a recent review of school leadership interventions cited New Leaders as

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[1] Gates, S.M., Baird, M.D., Doss, C.J., Hamilton, L.S., Opper, I.M., Master, B.K., Tuma, A.P., Vuollo, M., Zaber, M.A., (2019). Preparing School Leaders for Success Evaluation of New Leaders' Aspiring Principals Program, 2012–2017. RAND Corporation RR–2812–NL.

Continued

the principal preparation program with the strongest evidence of positive impact on student achievement.[2]

New Leaders is committed to getting a well-prepared, well-supported principal in every school so that our Nation's teachers and students can thrive. We can reach this goal by paying more attention to how our schools—not just individual classrooms, but all classrooms within a school—are organized and led. More than a decade of research shows that well-prepared, well-supported principals have a huge influence on teacher practice and student success. School leaders account for 25 percent of a school's impact on student learning, [3] and an above-average principal can improve student achievement by 20 percentage points.[4] Moreover, outstanding school leaders attract and retain great educators: fully 97 percent of teachers list principal quality as critical to their retention and career decisions—more than any other factor.[5] And school leaders transform the lowest-performing schools, where the positive effects of strong leadership on student achievement are most pronounced.[6] In fact, a landmark study found "virtually no documented instances of troubled schools being turned around without intervention by a powerful leader." [7]

We were pleased that the Every Student Succeeds Act (ESSA) maintained and strengthened the School Leader Recruitment and Support Program (SLRSP). However, we were deeply dismayed to see funding for SLRSP zeroed out in recent spending deals.

The School Leader Recruitment and Support Program (SLRSP) was authorized under ESSA with bipartisan support and is the only Federal program with an exclusive focus on evidence-based school leadership interventions for high-need schools. SLRSP updates the School Leadership Program (SLP), the program included in the previous version of the Elementary and Secondary Education Act, and provides districts with resources to develop and support dynamic leaders who have a measurable, positive impact on student achievement. The program empowers eligible entities—including State or local educational agencies—to pursue a range of activities in support of school leadership for high-need schools, such as the development and implementation of leadership training programs, the provision of ongoing professional development for school leaders, and the dissemination of best practices regarding the recruitment and retention of highly effective school leaders. In addition, eligible entities may carry out projects in partnership with nonprofit organizations and institutions of higher education. Finally, under priorities set forth in the reauthorized statute, SLRSP incentivizes eligible entities to focus on principal preparation and professional development practices for which there is evidence of effectiveness, as demonstrated through rigorous research.

As implementation of ESSA moves to the State, local, and school levels, it is more important than ever that we ensure every school is led by an outstanding principal- a focus that can lead to incredible results for kids while representing a cost-effective use of Federal resources. According to a national analysis, the average cost to recruit, prepare, and hire a new principal is $75,000.[8] Because 12 percent of principals leave the profession every year, replacing each requires significant resources—upwards of $200 million for the Nation's high-need schools. That same analysis found that the average cost of principal support is $16,500—requiring more than $350 mil-

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Gates, S., Hamilton, L., Martorell, P., et. al. (2014). Preparing Principals to Raise Student Achievement: Implementation and Effects of the New Leaders Program in Ten Districts. The RAND Corporation. Retrieved from http://www.rand.org/pubs/research__reports/RR507.html.

[2] Herman, R., Gates, S. M., Chavez-Herrerias, E. R., and Harris, M. (2016). School Leadership Interventions Under the Every Student Succeeds Act (Volume I). The RAND Corporation. Retrieved from http://www.rand.org/content/dam/rand/pubs/research__reports/RR1500/RR1550/RAND__RR1550.pdf.

[3] Leithwood, K., Seashore Louis, K., Anderson, S., & Wahlstrom, K. (2004). How leadership influences student learning: A review of research for the Learning from Leadership Project. New York, NY: The Wallace Foundation. Retrieved from http://www.wallacefoundation.org/knowledge-center/Pages/How-Leadership-Influences-Student-Learning.aspx.

[4] Marzano, R. J., Waters, T., & McNulty, B. A. (2005). School leadership that works: From research to results. Alexandria, VA: Association for Supervision and Curriculum Development.

[5] Scholastic Inc. (2012). Primary Sources: America's Teachers on the Teaching Profession. New York, NY: Scholastic and the Bill and Melinda Gates Foundation. Retrieved from http://www.scholastic.com/primarysources/pdfs/Gates2012__full.pdf.

[6] Seashore Louis, K., Leithwood, K., Wahlstrom, K., & Anderson, S. (2010). Investigating the links to improved student learning. Washington, DC: Wallace Foundation. Retrieved from http://www.wallacefoundation.org/knowledge-center/Pages/Investigating-the-Links-to-Improved-Student-Learning.aspx.

[7] Leithwood, K., Seashore Louis, K., Anderson, S., & Wahlstrom, K. (2004).

[8] School Leaders Network. (2014). Churn: The High Cost of Principal Turnover. Retrieved from http://connectleadsucceed.org/sites/default/files/principal__turnover__cost.pdf#page=1&zoom=auto,-15,792.

lion annually to mentor and support the leaders of high-need schools. Though the need is great, investments in leadership are extremely cost-effective: supporting one principal is actually an investment in the 25 teachers and 500 or more students that he or she, on average, supports. In fact, a National Governors Association report describes how slightly shifting the balance of educator investments toward principals is a smart way to improve school working conditions to foster stronger teaching and better outcomes for kids.[9] Further, strategies to address principal burnout, which disproportionately affects high-need schools,[10] can yield huge cost savings.[11]

The Federal Government has a crucial role to play in advancing innovation and sharing best practices with the field so that State and local leadership strategies, especially for high-need schools, can be strengthened, now and in the future, by a strong and growing evidence base. The SLP helped launch and expand some of the country's most innovative and effective leadership development programs, including New Leaders, New Teacher Center, NYC Leadership Academy, and TNTP. Since receiving SLP grants, these organizations have grown exponentially to reach many more schools, teachers, and students in high-need communities—greatly expanding the impact of the Federal Government's initial investment. Further, SLP grantees, including those affiliated with the University Council of Educational Administrators (UCEA), have demonstrated a remarkable commitment to programmatic evaluation, continuous improvement, and transparency. By proactively sharing their lessons and resources open-source with the field, these organizations have helped to galvanize dramatic changes to the principal preparation sector as a whole[12]—inspiring necessary changes to the way principals are trained to lead our Nation's schools in States and districts across the country.

It is worth noting that while there are other programs that can support effective school leadership programs and strategies, the reality is that leadership has historically been overlooked and consistently underfunded. In fact, for the past several years more than two-thirds of districts have invested zero Federal professional development funds on school leaders.[13] Without SLRSP, we lose a key Federal lever for seeding the next generation of effective principal development programs, promoting equity, advancing ongoing innovation, and sharing cutting-edge school leadership lessons with the broader field. It is absolutely crucial that we reinstate this dedicated funding source.

We urge Congress to restore funding for SLRSP at $14.5 million to support innovative, evidence-based school leadership programs and partnerships that promise a return for students, schools, and communities that far exceeds this targeted investment.

Thank you for the opportunity to provide the views of New Leaders on the fiscal year 2020 appropriations. If you would like to discuss our recommendations, please do not hesitate to contact policyteam@newleaders.org.

[This statement was submitted by Jean Desravines, CEO, New Leaders.]

PREPARED STATEMENT OF THE NEZ PERCE TRIBE

Honorable Chairman and members of the Committee, the Nez Perce Tribe (Tribe) would like to thank you for the opportunity to provide recommendations to the Committee as it evaluates and prioritizes fiscal year 2020 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.

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[9] National Governors Association. (2015). Improving Educational Outcomes: How State Policy Can Support School Principals as Instructional Leaders. Washington, DC: National Governors Association. Retrieved from https://www.nga.org/files/live/sites/NGA/files/pdf/2015/1506SupportingPrincipals.pdf.

[10] According to 2014 data from the National Center for Education Statistics, high-need schools must also grapple with an overall principal turnover rate of 28 percent, significantly higher than schools in more affluent communities.

[11] According to School Leaders Network (2014), up to $330,000 annually for a typical urban district.

[12] University Council for Educational Administration and New Leaders. (2016). State Evaluation of Principal Preparation Programs Toolkit. Retrieved from www.sepkit.org.

[13] U.S. Department of Education (2015). Findings from the 2014–15 Survey on the Use of Funds Under Title II, Part A. U.S. Department of Education (2014). Findings from the 2013–14 Survey on the Use of Funds Under Title II, Part A. U.S. Department of Education (2013). Findings from the 2012–13 Survey on the Use of Funds Under Title II, Part A. All retrieved from http://www2.ed.gov/programs/teacherqual/resources.html.

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 2020 appropriations recommendations for these agencies.

The Tribe recommends $20 billion be provided for Title I, Part A of the Every Student Succeeds Act Local Education Agency Grants. Rural public schools on the Reservation use this funding to address the obstacles low-income students face meeting academic standards.

The Tribe recommends $6.9 million be allocated for the State-Tribal Education Partnership Program (STEP) authorized in Title VI, Part A, Subpart 3 of the Every Student Succeeds Act. The Tribe is one of the participants in the STEP which provides an avenue for States and tribes to work together to improve and enhance education delivery and parent involvement in areas with high populations of tribal students. The STEP has been a success for the Tribe and continued funding is needed to keep the program active.

The Tribe recommends the same amount be allocated in fiscal year 2020 as was allocated in fiscal year 2019 for Impact Aid, $1.446 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 $10 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 the $10.063 billion provided for Head Start in fiscal year 2019 be maintained for fiscal year 2020. Indian Head Start needs to be fully funded as these programs play a vital role in school readiness, child development, and early education for over 24,000 Native children. The Indian Head Start programs address the whole child from a health, cultural, and education perspective. These programs operate on slim budgets but provide extraordinary returns in ensuring children are as prepared as possible to begin their education journey.

The Tribe recommends the fiscal year 2019 funding levels be maintained in fiscal year 2020 for all Tribal Behavioral Health Grants under the Substance Abuse and Mental Health Services Administration. The grants address a wide range of mental health and substance abuse issues such as youth suicide, opioid addiction, and methamphetamine addiction that are prevalent on the Reservation and threaten to overwhelm the Tribe's Social Services Department and health clinic. In addition, the competitive grants and tribal set-asides provided for promoting safe and stable families, child welfare services, and child abuse prevention should be maintained at fiscal year 2019 levels as well.

The Tribe appreciates the fiscal year 2019 funding of $50 million to address the opioid crisis in Indian Country. However, this funding pales in comparison to the $1.5 billion that has been provided to States on this issue through the 21st Century Cures Act and fiscal year 2019 funding. The Tribe recommends funding to address opioid use and its effects on communities be increased and also made available in forms other than grants. Indian Country suffers from opioid addiction at a higher rate than most communities and all communities need access to monies to help address this problem. Funding in the form of grants places a high administrative burden on tribes and forces tribes to compete against each other unnecessarily. Several members of Congress have also voiced concern over such methodologies for tribal funding.

The Tribe recommends $60.5 million be allocated to the Department of Labor's Division of Indian and Native American Programs, an increase of $6 million over fiscal year 2019 funding. The Workforce Innovation and Opportunity Act, Section 166 Indian and Native American Programs serve the training and employment needs of tribes through programs such as the Indian Employment, Training, and Related Services Demonstration Act of 1992. The Tribe has used this funding to provide important programs that have helped develop the workforce and economy on the Reservation. This program has been very successful but will not continue without funding.

The Tribe also recommends providing funding for the Public Service Loan Forgiveness program (PSLF). The PSLF was established with the passage of the College Cost Reduction and Access Act of 2007, and was created to encourage individuals to enter lower-paying but vitally important public sector jobs such as military service, law enforcement, public education, and public health professions. The PSLF allows eligible borrowers to qualify for forgiveness of the remaining balance of their William D. Ford Federal Direct Loan Program loans after they have served full time at a public service organization for at least 10 years, while making 120 qualifying payments. The PSLF has shown to be a valuable tool for tribal governments in the recruitment of employees and an important resource for students to address educational debt while serving in jobs that may not be as financially lucrative as positions in the private sector. Most tribes are located in rural areas and face challenges in recruiting and retaining employees. This program has been useful in that regard and the Tribe recommends the program not be eliminated.

Thank you for your consideration of the Tribe's requests with respect to these fiscal year 2020 appropriations.

PREPARED STATEMENT OF THE NORTHWEST PORTLAND AREA INDIAN HEALTH BOARD

Greetings Chairman Blunt and Ranking Member Murray and Members of the Subcommittee. My name is Andy Joseph, Jr., and I serve as Chairman of the Northwest Portland Area Indian Health Board (NPAIHB), Vice Chair on the Colville Business Council, and Co-Chair of the IHS National Tribal Budget Formulation Workgroup. I thank you for this opportunity to provide testimony on fiscal year 2020 appropriations to the Senate Subcommittee on Labor, Health and Human Services, Education, and Related Agencies for the Department of Health and Human Services (HHS).

Established in 1972, the NPAIHB is a Tribal organization established under the Indian Self-Determination and Education Assistance Act (ISDEAA), Public Law 93–638, advocating on behalf of the 43 federally-recognized Indian Tribes in Idaho, Oregon, and Washington on specific healthcare issues. NPAIHB operates the Northwest Tribal Epidemiology Center (NWTEC) and a variety of important health programs on behalf of our member Tribes and national programs that serve Indian country.

OFFICE OF THE SECRETARY

Fund Minority HIV/AIDS Fund—formerly known as the Office of the Secretary-Secretary's Minority AIDS Initiative Fund (SMAIF). Congress appropriates an average of $50 million to the Office of the HHS Secretary for General Department Management (GDM) to SMAIF. The HHS Secretary delegates these funds to other agencies to be used for MAI-related activities, which support programs that distinctly target communities of color. In fiscal year 2018, $3.6 million (1.5 percent) of SMAIF dollars were allocated to IHS for HIV/AIDS and HCV prevention, treatment, outreach and education—out of the total $53.9 million of SMAIF dollars. NPAIHB has several successful SMAIF projects:

STD/HIV/HCV GPRA Measurement: The project is monitoring STD/HIV GPRA measures for IHS sites throughout Indian Country.

HCV–ECHO: The project works closely with I/T/U providers to screen, manage and treat patients infected with HIV/AIDS and HCV within existing systems I/T/U clinics Nation-wide.

Native Youth HIV Prevention and Outreach: We R Native is a comprehensive, multimedia health resource for Native youth, by Native youth. The service includes an interactive website (www.weRnative.org), a text messaging service (Text NATIVE to 97779), a Facebook page, a YouTube channel, Instagram, Twitter, and print marketing materials. Special features include 100+ Youth Ambassadors and an "Ask Auntie" Question and Answer (Q&A) service.

Disseminating Effective Interventions: The website www.HealthyNativeYouth.org is a one-stop-shop for Tribal health advocates to access engaging, age-appropriate sexual health curricula for AI/AN youth.

Continued appropriation to SMAIF and inclusion of Indian Country in allocation of these dollars is necessary to maintain staffing, capacity, and organizational infrastructure to address health disparities for not only our Northwest Tribes, but also Tribes across Indian Country. Any elimination of SMAIF funding for IHS will dissolve almost all current HIV and HCV efforts and programs in Indian Country. For fiscal year 2020, for SMAIF, NPAIHB recommends at least $57.5 million with at least $7.2 million to IHS.

Support National HIV and HCV Elimination Strategy. President Trump announced in his State of the Union remarks a commitment to end HIV transmissions within 10 years. NPAIHB supports a national effort to end HIV but cautions that the plan will succeed only if it addresses all people living with HIV and all people at risk of HIV. We urge the Administration to provide concrete next steps for the plan to end HIV transmission within 10 years that includes Tribes and AI/AN people. While rates of new HIV diagnoses are not elevated in AI/AN compared to some other race/ethnicities, there are notable concerns: (1) new HIV diagnoses among AI/AN increased by 70 percent from 2011 to 2016; (2) AI/AN patients have had the lowest survival rates of any race/ethnicity after an AIDS diagnosis; and (3) both male and female AI/AN had the highest percent of estimated diagnoses of HIV infection attributed to injection drug use (IDU). In addition, most of Indian Country is rural, where barriers to HIV education can exacerbate stigma, and reaching specialists for HIV is more problematic than in an urban setting (https://www.cdc.gov/hiv/pdf/group/racialethnic/aian/cdc-hiv-natives.pdf). Given this data, NPAIHB recommends a significant increase of HIV funding to Indian Country to increase Tribes' and Tribal organizations' ability to maintain and increase ongoing HIV prevention, treatment, and outreach efforts. Moreover, funding for "Ending the HIV Epidemic: A Plan for America" should not be limited to jurisdiction 1 locations, and should be available to all Tribes and Tribal organizations to end the HIV epidemic.

It is estimated that $600 million is needed to treat all AI/AN with HCV served by an IHS, Tribal and urban Indian facility (I/T/U). Therefore, NPAIHB recommends the "Ending the HIV Epidemic: A Plan for America" should include $120 million for HCV (for 5 years) and $30 million for HIV for fiscal year 2020. These funds for HIV and HCV are the minimum amount needed for clinical prevention, treatment and management of HIV and HCV at I/T/U clinics and NPAIHB supports retention of these funds at a national level for a coordinated effort for treatment. Any funds needed for community level prevention, outreach and education at the Tribal level would need an additional allocation of funds.

CENTERS FOR MEDICARE AND MEDICAID SERVICES

Oppose Medicaid State Block Grant and Per Capita Programs. NPAIHB disagrees with the President's proposal for fiscal year 2020 to change the Medicaid program to State block grants or a per-capita program. This change would essentially shift the trust responsibility from the Federal Government to States. This responsibility must remain with the Federal Government to uphold treaty and trust obligations and ensure that Tribes continue to receive Medicaid reimbursement. NPAIHB recommends that I/T/Us be exempt from any Medicaid block grant or per capita program.

Support Patient Protection and Affordable Care Act (ACA)/Indian Health Care Improvement Act (IHCIA). The Patient Protection and Affordable Care Act (ACA) has provided an incredible opportunity for increased access to health insurance for Tribal members in our area. Many Northwest Tribes implemented premium sponsorship programs for their Tribal members. The increased access for AI/AN people to healthcare through the Marketplaces has improved the health of many AI/ANs, while the increase of third party revenue to I/T/Us has expanded programs and services at I/T/Us. There are also several important Indian-specific provisions in the ACA that are critical to the Indian health system. Section 2901(b) ensures that I/T/Us are the payers of last resort; Section 2901(c) simplifies eligibility determinations for AI/AN enrolling in CHIP when seeking services from Indian providers; Section 2902 authorizes I/T/Us reimbursement for Medicare Part B services; and Title IX, Section 9021 ensures that health benefits provided by a Tribe to Tribal members are not counted as taxable income. In addition, IHCIA, permanently reauthorized under the ACA, has created opportunities to improve access and financing of healthcare services for AI/ANs. NPAIHB respectfully asks that HHS protect and strengthen the ACA and IHCIA to ensure Tribes and AI/ANs continue to reap the benefits of these laws.

SUBSTANCE ABUSE AND MENTAL HEALTH SERVICES ADMINISTRATION

Increase Funding Tribal-Specific Programs. Northwest Tribes are particularly concerned about our children and youth. Suicide is the second leading cause of death for adolescents and young adults. In the Portland Area, Tribes lack access to youth-focused prevention and recovery services. For fiscal year 2020, we request increases to SAMHSA Tribal programs: fund Tribal Behavioral Health Grant program at $50 million with $25 million for mental health and $25 million for substance abuse (funded in fiscal year 2019 at $40 million—$20 for mental health and $20 million for substance abuse); fund Garrett Lee Smith Suicide Prevention Tribal Set Aside at $3.5 million (funded in fiscal year 2019 at $2.9 million); fund Zero Prevention Initiative at $3 million (funded in fiscal year 2019 at $2.2 million); and fund Tribes under the National Child Traumatic Stress Initiative (NCTSI) at $1.5 million ($1 million set aside in fiscal year 2019).

Continue Opioid Crisis and Funding. While NPAIHB appreciates the $50 million set-aside for Tribes and Tribal organizations for Tribal Opioid Response (TOR) funding and the $10 million set aside for Medication Assisted Treatment (MAT) for Tribes, which is crucial for Tribal clinics to administer MAT, it is not enough funding. We request that SAMHSA continue SAMHSA TOR non-competitive funding for Tribes, directly to Tribes and in parity with States, and increase funding term to three to 5 years; increase TOR funding to $100 million in fiscal year 2021 (funded at $50 million in fiscal year 2019); and increase Tribal set-aside for MAT funding to $15 million (funded at $10 million in fiscal year 2019). TOR funding must also be flexible to address other and co-occurring substance use issues (alcohol, methamphetamines, etc.) and mental health issues; and allow for prevention activities.

SAMHSA must reconsider TOR GPRA reporting for all Tribes and Tribal organizations receiving SAMHSA TOR and MAT funding. The instrument is lengthy and takes 35–45 minutes per patient to complete; and is required to be completed with each patient at 0, 6 and 12 months for MAT and other activities. This is a burden on staff of our Tribes and Tribal organizations and impacts patient care. NPAIHB recommends that GPRA reporting be optional, not mandatory, and consistent with IHS GPRA reporting requirements for self-governance Tribes.

Support Comprehensive Funding for Other Substance Use Disorders. Other substance use issues, including alcohol, methamphetamines, heroin and other substances, not just opioids, continue to impact our communities. Misuse of prescription opioids commonly leads to the use of other drugs, such as heroin in Tribal communities. The National Institute of Drug Abuse noted that 21 to 29 percent of patients prescribed opioids for chronic pain misuse them, and 4 to 6 percent who misuse prescription opioids transition to heroin. Furthermore, the death rate for heroin overdoses among AI/ANs have dramatically increased, rising 236 percent from 2010 to 2014.[1] NPAIHB recommends increased funding to prevent and address other substance use disorders and/or flexibility in opioid funding to prevent and address cooccuring substance use disorders and mental health issues.

Fund Tribal Epidemiology Centers. Thirty-four (34) Tribes in our area are receiving TOR funding; and twenty-three (23) of the 34 Tribes applied through the NPAIHB because they did not have enough time or capacity to apply on their own. Many Tribes found the application to be time-consuming, burdensome and were concerned that the funding was not adequate to meet the TOR requirements. Our Tribes relied on our Northwest Tribal Epidemiology Center (NWTEC) to coordinate the consortium of 23 Tribes and to provide technical assistance which Tribes funded through their TOR funds but there should be a specific set-aside for Tribal Epidemiology Centers to coordinate consortiums and to provide training and technical assistance. NPAIHB recommends set-aside funding for Tribal Epidemiology Centers of $2.5 million for administration of TOR consortiums and/or training and technical assistance.

CENTERS FOR DISEASE CONTROL AND PREVENTION

Fund Good Health and Wellness in Indian Country (Under Racial and Ethnic Approaches to Community Health (REACH)) at $32 million. The Good Health and Wellness in Indian Country initiative supports efforts by American Indian and Alaska Native communities to implement holistic and culturally adapted approaches to reduce tobacco use, improve physical activity and nutrition, and increase health literacy. NPAIHB recommends that Good Health and Wellness in Indian Country program be funded at $32 million for fiscal year 2020.

Include Tribes in HIV/HCV Funding Opportunities. The NPAIHB would like to see base funding for HIV/HCV testing, prevention, and treatment in Tribal communities. As sovereign nations, Tribes share a unique relationship with the Federal Government. However, funding for HIV/HCV prevention and education generally flows to States via block grants. This system leaves many Tribes with limited resources, and forces Tribes to compete with States for funding. Base funding for HCV in Indian Country would further the goals of the U.S. National Viral Hepatitis Action Plan for 2017–2020, which identifies AI/ANs as one of the primary target populations for reducing new HCV infections and HCV-related deaths. Base funding for HIV in Indian Country would support Tribes and Tribal organizations to realize the "Ending the HIV Epidemic: A Plan for America." Therefore, NPAIHB recommends

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[1] Dan Nolan and Chris Amico, How Bad is the Opioid Epidemic?,PBS.org (Feb. 23, 2016), available at https://www.pbs.org/wgbh/frontline/article/how-bad-is-the-opioid-epidemic/.

an appropriation of direct, formula-based funding to Tribes and Tribal organizations for HIV and HCV prevention, testing, and treatment for fiscal year 2020.

Thank you for this opportunity to provide our recommendations on the fiscal year 2020 HHS appropriations to the Senate Subcommittee on Labor, Health and Human Services, Education, and Related Agencies for the HHS. I invite you to visit our Portland Area Tribes to learn more about the utilization of HHS funding and healthcare and social service needs in our Area.[2]

[This statement was submitted by Andrew Joseph, Jr., Chairman, Northwest Portland Area Indian Health Board.]

PREPARED STATEMENT OF THE NURSING COMMUNITY COALITION

The Nursing Community Coalition is comprised of 62 national nursing organizations who work together to advocate and advance healthcare issues that impact education, research, practice, and regulation. Collectively, the Nursing Community Coalition represent Registered Nurses (RNs), Advanced Practice Registered Nurses (including Certified Nurse-Midwives, Nurse Practitioners, Clinical Nurse Specialists, and Certified Registered Nurse Anesthetists), nurse executives, nursing students, faculty, and researchers, as well as other nurses with advanced degrees. The Nursing Community Coalition respectfully requests that Congress continues their strong investment in nursing education and research in fiscal year 2020 by supporting $266 million for the Nursing Workforce Development programs (authorized under Title VIII of the Public Health Service Act [42 U.S.C. 296 et seq.]), administered by the Health Resources and Services Administration (HRSA), and $173 million for the National Institute of Nursing Research (NINR), one of the 27 Institutes and Centers within the National Institutes of Health (NIH).

PROMOTING AMERICA'S HEALTH THROUGH NURSING CARE

As the largest group of health professionals, with more than four million licensed practitioners in the country, nurses are integral members of the healthcare team.[1] Nurses and other healthcare professionals work together and consistently provide high-quality patient-centered care in all communities, especially in rural and underserved areas.

Title VIII Nursing Workforce Development programs help meet this demand by connecting patients with care across a variety of settings, including in community health centers, hospitals, long-term care facilities, local and State health departments, schools, workplaces, and patients' homes. A prime example is through Title VIII's Advanced Nursing Education (ANE) program. In Academic Year 2016–2017, ANE programs supported 10,537 students, including those in Advanced Education Nursing Traineeships (AENT) and Nurse Anesthetist Traineeships (NAT).[2] In fact, 80 percent of AENT recipients received training in primary care settings, and 75 percent of NAT recipients were trained in medically-underserved areas.[3]

It is imperative that we continue to promote a diverse nursing pipeline that reflects an increasingly diverse population, which bolsters positive patient outcomes. Under the Title VIII Nursing Workforce Diversity program, 4,416 students were trained in the 2016–2017 Academic Year.[4] All of these trainees, were from underrepresented groups and/or from disadvantaged backgrounds.[5]

The Nursing Community respectfully requests $266 million for the Title VIII Nursing Workforce Development programs in fiscal year 2020, which include the following:

—Advanced Nursing Education Program (Sec. 811), including the Advanced Education Nursing Traineeships and Nurse Anesthetist Traineeships

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[2] For more information, please contact Laura Platero, NPAIHB, at lplatero@npaihb.org.

[1] National Council of State Boards of Nursing. (2019). Active RN Licenses: A profile of nursing licensure in the U.S. as of April 5, 2019. Retrieved from: https://www.ncsbn.org/6161.htm.

[2] Department of Health and Human Services fiscal year 2019 Health Resources and Services Administration Justification of Estimates for Appropriations Committees. https://www.hrsa.gov/sites/default/files/hrsa/about/budget/budget-justification-fy2019.pdf.

[3] Department of Health and Human Services fiscal year 2019 Health Resources and Services Administration Justification of Estimates for Appropriations Committees. https://www.hrsa.gov/sites/default/files/hrsa/about/budget/budget-justification-fy2019.pdf.

[4] Department of Health and Human Services fiscal year 2019 Health Resources and Services Administration Justification of Estimates for Appropriations Committees. https://www.hrsa.gov/sites/default/files/hrsa/about/budget/budget-justification-fy2019.pdf.

[5] Department of Health and Human Services fiscal year 2019 Health Resources and Services Administration Justification of Estimates for Appropriations Committees. https://www.hrsa.gov/sites/default/files/hrsa/about/budget/budget-justification-fy2019.pdf.

—Nursing Workforce Diversity (Sec. 821)
—Nurse Education, Practice, Quality, and Retention (Sec. 831)
—NURSE Corps Loan Repayment and Scholarship Program (Sec. 846)
—Nurse Faculty Loan Program (Sec. 846A)
—Comprehensive Geriatric Education Program (Sec. 865)

Establishing Scientific Basis for Quality Patient Care:

For more than three decades, scientific endeavors funded at the National Institute of Nursing Research (NINR) have been essential to advancing the health of individuals, families, and communities. As one of 27 Institutes and Centers at the National Institutes of Health (NIH), NINR's research projects are aimed at reducing burdensome chronic illness, improving end of life care, and promoting patient-centered care across the life continuum. NINR's Strategic Plan includes the themes of symptom science for patients with chronic illness and pain; wellness to prevent illness across conditions, settings, and the lifespan; patient self-management to improve quality of life; and end-of-life and palliative care science.[6] From disease prevention and global health, to precision medicine and genomic studies, NINR is at the forefront of nursing science and research and training new nurse scientists to sustain the longevity and success of this important endeavor.

The Nursing Community respectfully requests $173 million for the NINR in fiscal year 2020.

We must continue to invest in the Title VIII Nursing Workforce Development programs and NINR to strengthen the foundational care nurses provide daily in communities across the country. Thank you for your support of these crucial programs.

59 Members of the Nursing Community Coalition Submitting this Testimony

Academy of Medical-Surgical Nurses
American Academy of Ambulatory Care Nursing
American Academy of Emergency Nurse Practitioners
American Academy of Nursing
American Association of Colleges of Nursing
American Association of Critical-Care Nurses
American Association of Heart Failure Nurses
American Association of Neuroscience Nurses
American Association of Nurse Anesthetists
American Association of Nurse Practitioners
American Association of Post-Acute Care Nursing
American College of Nurse-Midwives
American Nephrology Nurses Association
American Nurses Association
American Nursing Informatics Association
American Organization for Nursing Leadership
American Pediatric Surgical Nurses Association, Inc.
American Public Health Association, Public Health Nursing Section
American Psychiatric Nurses Association
American Society for Pain Management Nursing
American Society of PeriAnesthesia Nurses
Association for Radiologic and Imaging Nursing
Association of Community Health Nursing Educators
Association of Pediatric Hematology/Oncology Nurses
Association of periOperative Registered Nurses
Association of Public Health Nurses
Association of Rehabilitation Nurses
Association of Veterans Affairs Nurse Anesthetists
Association of Women's Health, Obstetric and Neonatal Nurses
Chi Eta Phi Sorority, Incorporated
Commissioned Officers Association of the U.S. Public Health Service
Dermatology Nurses' Association
Emergency Nurses Association
Friends of the National Institute of Nursing Research
Gerontological Advanced Practice Nurses Association
Hospice and Palliative Nurses Association
Infusion Nurses Society
International Association of Forensic Nurses
International Society of Psychiatric-Mental Health Nurses
National Association of Clinical Nurse Specialists
National Association of Neonatal Nurse Practitioners
National Association of Neonatal Nurses
National Association of Nurse Practitioners in Women's Health

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

National Association of Pediatric Nurse Practitioners
National Association of School Nurses
National Black Nurses Association
National Council of State Boards of Nursing
National Forum of State Nursing Workforce Centers
National League for Nursing
National Nurse-Led Care Consortium
National Organization of Nurse Practitioner Faculties
Nurses Organization of Veterans Affairs
Oncology Nursing Society
Organization for Associate Degree Nursing
Pediatric Endocrinology Nursing Society
Preventive Cardiovascular Nurses Association
Society of Pediatric Nurses
Society of Urologic Nurses and Associates
Wound, Ostomy and Continence Nurses Society

[This statement was submitted by Rachel Stevenson, Executive Director, Nursing Community Coalition.]

PREPARED STATEMENT OF ONE VOICE AGAINST CANCER

Fiscal year 2020 Appropriations for the National Institutes of Health, the National Cancer Institute and the Division of Cancer Prevention and Control at the Centers for Disease Control and Prevention

Submitted for the record to the Senate Appropriations Subcommittee on Labor, Health and Human Services, and Education and Related Agencies—April 5, 2019

One Voice Against Cancer (OVAC) is a broad coalition of public interest groups representing millions of cancer patients, researchers, providers, survivors and their families, delivering a unified message to Congress and the White House on the need for increased funding for cancer research and prevention priorities.

The more than 200 diseases that we call "cancer" take a tremendous toll on our Nation. It is estimated that more than 1.7 million people in the U.S. will be diagnosed with cancer this year. Additionally, more than 606,000 Americans will die from the disease in 2019, which translates to more than 1,660 people a day. Recent estimates show that cancer costs the U.S. economy more than $216 billion annually in direct treatment costs and lost productivity, a number that will increase dramatically as incidence rates climb. Additionally, it has been projected that 2.1 million people in the U.S. will be diagnosed in 2030.

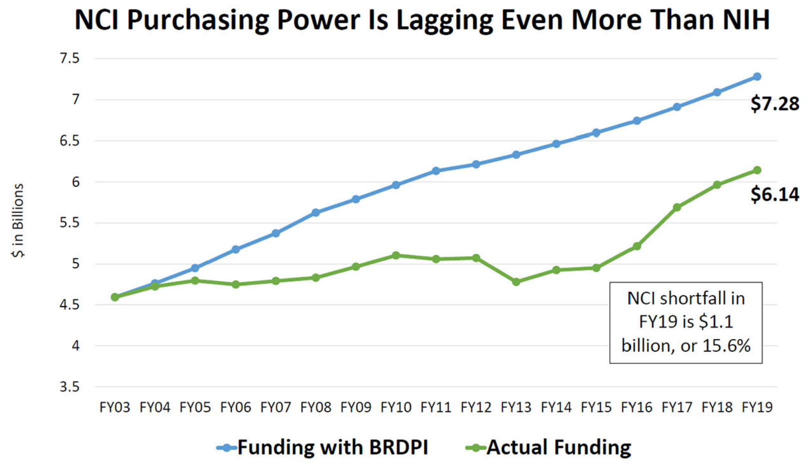
For the last 50 years, every major medical breakthrough in cancer can be traced back to the National Institutes of Health (NIH) and the National Cancer Institute (NCI). We know that investment in research at the NIH and NCI leads to lives saved.

Because of the previous investment in cancer research, more than 15.5 million American cancer survivors are alive today, and we are enjoying a quarter century of sustained declines in cancer mortality. As of 2016, the cancer death rate for men and women combined has fallen 27 percent from its peak in 1991. This decline translates to about 1.5 percent per year and more than 2.6 million deaths avoided between 1991 and 2016.

Additionally, more than 80 percent of Federal funding for the NIH and NCI is spent on biomedical research projects at local research facilities across the country. In fiscal year 2018, the NIH provided over $28 billion in extramural research to scientists in all 50 States and the District of Columbia. NIH research funding also supported more than 433,000 jobs and nearly $74 billion in economic activity last year.

Thanks to your leadership, significant progress has been made to reduce the loss of purchasing power experienced by the NIH and NCI since fiscal year 2003, which marked the end of the five-year doubling of NIH. However, NIH funding is still 8.4 percent less than what it would have been if funding had simply kept up with biomedical inflation.

With increases in Federal investment in medical research over the last four fiscal years and the passage of the 21st Century Cures Act that included funding for the National Cancer Moonshot Initiative, Congress has demonstrated its bipartisan support for cancer research. However, Moonshot funding is actually a small percentage of NCI's total budget and in fiscal year 2020 the funding going to NCI for this initiative will be cut almost in half, from $400 million in fiscal year 2019 to $195 million in fiscal year 2020. Even counting the Cancer Moonshot, NCI's budget lags 15.6 percent, or $1.1 billion, below what it would have been if funding had kept pace with biomedical inflation since fiscal year 2003.



To continue the progress that has led to medical breakthroughs for treatment and therapies for millions of cancer patients, NIH and NCI need an increased, sustainable Federal investment. Therefore, OVAC urges Congress to provide the NIH with at least a $41.6 billion in fiscal year 2020. Additionally, we urge you to provide at least a $378 million increase for NCI, for a total of $6.522 billion, as reflected in the Professional Judgment Budget Proposal for fiscal year 2020 provided to Congress by the NCI. (https://www.cancer.gov/about-nci/budget/plan/)

Although great progress has been seen in the fight against cancer, not all populations are benefitting from this progress. That's why the Division of Cancer Prevention and Control (DCPC) at the Centers for Disease Control and Prevention (CDC) continues to play a key role in bringing evidence-based interventions developed by NIH and NCI to underserved groups. This division provides vital resources to every State for cancer monitoring and surveillance, State cancer control planning and implementation, survivorship programs, and screening and awareness initiatives targeting breast, cervical, skin, prostate, colon, and ovarian cancers.

However, in sharp contrast to NIH, funding for the DCPC has remained virtually flat for 9 years, rising just $1.2 million from fiscal year 2010 ($370.3 million) to fiscal year 2019 ($371.5 million). Congress has a rare opportunity to reverse this trend. OVAC urges Congress to provide at least $555 million to CDC's evidence-based cancer prevention and control programs, which are saving lives in communities across the country.

Within the DCPC, OVAC requests at least $70 million, an increase of $19 million, for the National Program of Cancer Registries (NPCR), which provides technical, operational, and financial support for States to manage cancer registries. The more accessible and usable registry data is, the more impact it can have on public health. CDC is working to enhance the use of NPCR cancer registry data through additional data collection, expanded electronic reporting, and innovative public health applications. Additional funding would allow the CDC to create a cloud-based system that would record data in real time and eliminate the current two-year lag in reporting.

Additionally, oncology nurses are on the front lines when it comes to providing quality cancer care and contribute significantly to cancer research. More funding for the Health Resources and Services Administration's nurse training programs is necessary to support more nursing scholarships and loan repayment applications and to address the current and future nursing workforce shortage.

Below please find an overview of OVAC's program level requests:

National Institutes of Health (NIH)—$41.584 billion, including:

—National Cancer Institute (NCI)—$6.522 billion

—National Institute on Minority Health and Health Disparities (NIMHD)—$331 million

—National Institute on Nursing Research (NINR)—$171 million

Centers for Disease Control and Prevention (CDC) Cancer Programs—$555 million, including:

—National Comprehensive Cancer Control Program—$50 million
—National Program of Cancer Registries—$70 million
—National Breast and Cervical Cancer Early Detection Program—$275 million
—Colorectal Cancer Control Program—$70 million
—National Skin Cancer Prevention Education Program—$5 million
—Prostate Cancer Awareness Campaign—$35 million
—Ovarian Cancer Control Initiative—$11 million
—Gynecologic Cancer and Education and Awareness (Johanna's Law)—$12 million
—Cancer Survivorship Resource Center—$900,000

HEALTH RESOURCES AND SERVICES ADMINISTRATION

—Title VIII Nursing Programs—$266 million

Once again, thank you for your continued leadership on funding issues important in the fight against cancer. Funding for cancer research and prevention must continue to be top budget priorities in order to increase the pace of progress in the fight against cancer. OVAC once again calls on Congress to sustain our Nation's commitment to cancer research and prevention by increasing support for these efforts.

PREPARED STATEMENT OF ANN D. PEEL

Mr. Chairman,

Amyloidosis is a rare and usually fatal disease. I ask that you include language in the Committee's report for fiscal year 2020 recommending that the National Institutes of Health (NIH) expand its research efforts into amyloidosis, a group of rare diseases characterized by abnormally folded protein deposits in tissues. I also ask that the Committee direct NIH to inform the Committee on the steps taken to increase the understanding of the causes of amyloidosis and the measures taken to improve the diagnosis and treatment of this devastating group of diseases.

Your Committee over the years has been instrumental in moving forward to finding the causes and a cure for amyloidosis.

Efforts made by NIH and Amyloidosis Centers around the country are increasing the awareness of this disease and many more people are diagnosed and treated for amyloidosis than a decade ago.

However, there is no known cure for amyloidosis and the causes for why amyloidosis occur remain elusive. I urge you to continue the efforts of this Committee to help people with amyloidosis have hope for the future.

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 16 years. This was due to the intensive, life-saving treatment that I have received through the Amyloidosis Center at Boston University School of Medicine and Boston Medical Center. I continue to participate in a clinical trial that looks for ways to diagnose and treat amyloidosis.

One of the major concerns is that current methods of treatment are risky and unsuitable for many patients. Even with successful initial treatment, amyloidosis remains a threat, since it can recur years later.

Due to research, there are new forms of treatment that are options for me and patients with recurring amyloidosis. These new treatment options were not available 16 years ago. They provide evidence that funding through Health and Human Services can make a difference.

I ask for your support in helping me turn what has been my life-threatening experience into hope for others.

AMYLOIDOSIS

I have been treated for primary amyloidosis, a blood or bone marrow disorder.

Amyloidosis occurs when wrinkled or misfolded proteins form amyloid fibrils and are deposited in organs, such as the heart, kidneys and liver. These misfolded proteins clog the organs until they no longer are able to function—sometimes at a very rapid pace.

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.

Researchers have not been able to determine the root cause of the disease or an effective low-risk treatment. Amyloidosis can literally kill people before they even know that they have the disease.

In addition to primary amyloidosis, there are also thousands of cases of inherited (familial) and age-related amyloidosis. The most common familial type of amyloidosis was found to be caused by mutations in a protein made in the liver. This is the form of amyloidosis that may be present in a significant number of African-Americans.

Older Americans are susceptible to heart disease due to amyloid formed from the non-mutated form of the same protein. Another type of amyloidosis, secondary or reactive amyloidosis, occurs in patients with chronic infections or inflammatory diseases.

There is no explanation for how or why amyloidosis develops. Although progress has been made in developing alternate forms of treatment for amyloidosis, there is still no known reliable cure.

All of these types of amyloidosis, left undiagnosed or untreated, are fatal.

AMYLOIDOSIS TREATMENT

The Amyloidosis Center at Boston University School of Medicine and Boston Medical Center, and other centers for amyloidosis treatment, have found that high dose intravenous chemotherapy followed by stem cell transplantation is an effective treatment in selected patients with primary amyloidosis. Abnormal bone marrow cells producing amyloidogenic precursor protein are killed through high dose chemotherapy, and the patient's own extracted blood stem cells are replaced in order to improve the recovery process.

The treatment of individuals identified with amyloidosis varies with each patient. It depends on the type of amyloidosis, the specific organ systems involved, and the extent of involvement. An exact course of the disease is unpredictable. Some patients have achieved remission of disease and major organ system improvement. Barring a cure for amyloidosis, the current treatment goal is to provide a complete remission and if not to induce a "durable" or long remission.

The high dose chemotherapy and stem cell transplantation and other new drugs have increased the remission rate and long-term survival dramatically. However, this treatment can also be life threatening and more research needs to be done to provide less risky forms of treatment.

RESEARCH

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

Amyloidosis is vastly under-diagnosed. Thousands of people die because they were not diagnosed or diagnosed too late. More needs to be done to alert health professionals to identify this disease. Although I was diagnosed at a very early stage of the disease, many people are diagnosed after the point that they are physically able to undertake treatment.

I believe there are many more cases of amyloidosis than are known, as the disease can escape diagnosis and patients die of "heart failure," "liver failure," etc. In reality, some of these people had amyloidosis. Perhaps amyloidosis is not as rare a disease as we think.

CURRENT INITIATIVES

Through the leadership of this Committee and the further involvement of the U.S. Government, a number of positive developments have occurred. Research supported by the National Institute of Neurologic Disorders and Stroke at NIH and the Office of Orphan Products Development at the Food and Drug Administration led to successful repurposing of a generic drug that markedly slows progression of familial amyloidosis.

Basic and clinical research at the Boston University Amyloidosis Center has increased: models of light chain (AL) amyloid disease have been developed; serum chaperone proteins that cause amyloid precursor protein misfolding are being identified; imaging techniques for the diagnosis of amyloid disease are being investigated;

and new clinical trials for primary and familial amyloidosis are underway. Federal funding for research, equipment and treatment has been an important element in progress to date. Further funding is essential to speed the pace of discovery for basic and clinical research.

REQUEST FOR FISCAL YEAR 2020

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, in its 2020 Committee report, continue its strong support for increasing amyloidosis research funding through NIH and to increase efforts to improve the diagnosis of this life threatening disease.

I want to use my experience with this rare disease to help save the lives of others. With your support more can be done to help me achieve my dream.

Thank you for your consideration.

PREPARED STATEMENT OF THE PERSONALIZED MEDICINE COALITION

Chairman Blunt, Ranking Member Murray and distinguished members of the subcommittee, the Personalized Medicine Coalition (PMC) appreciates the opportunity to submit testimony on the National Institutes of Health (NIH) fiscal year 2020 appropriations. PMC is a nonprofit education and advocacy organization comprised of more than 230 institutions from across the healthcare spectrum. As the subcommittee begins work on the fiscal year 2020 Labor, Health and Human Services, Education and Related Agencies appropriations bill, we ask that the NIH receive an appropriation of at least $41.6 billion in fiscal year 2020, a $2.5 billion, or 6.4 percent, increase over fiscal year 2019 program level funding. This funding level would allow for meaningful growth above inflation in the base budget that would expand NIH's capacity to support promising science in all disciplines. It also would ensure that funding from the Innovation Account established in the 21st Century Cures Act would supplement the NIH's base budget, as intended, through dedicated funding for specific programs.

Personalized medicine, also called precision or individualized medicine, is an evolving field in which physicians use diagnostic tests to identify specific biological markers, often genetic, that help determine which medical treatments will work best for each patient. By combining this information with an individual's medical records, circumstances, and values, personalized medicine allows doctors and patients to develop targeted treatment and prevention plans. Personalized healthcare promises to detect the onset of and pre-empt the progression of disease as well as improve the quality, accessibility, and affordability of healthcare.[1]

I. THE ROLE OF NIH IN PERSONALIZED MEDICINE

The number of personalized medicines approved by the U.S. Food and Drug Administration (FDA) annually has increased from 5 percent of new drugs in 2005[2] to a record 42 percent in 2018.[3] For each of the past 4 years, personalized medicines have accounted for more than a quarter of new drugs approved in the United States.[4] Biopharmaceutical companies nearly doubled their R & D investment in personalized medicines over the last 5 years, and expect to increase their investment by an additional third over the next 5 years.[5] Leading manufacturers have identified scientific discovery as the biggest challenge facing personalized medicine, followed closely by regulatory and reimbursement barriers.

As the primary Federal agency conducting and supporting basic and translational research investigating the causes, treatments and cures for both common and rare diseases, NIH is leading scientific discovery for personalized medicines. Many institutes and centers at the NIH are supporting research that is informing the development of personalized medicines, including the National Human Genome Research Institute (NHGRI), the National Cancer Institute (NCI), The National Institute on

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[1] http://www.personalizedmedicinecoalition.org/Userfiles/PMC-Corporate/file/The-Personalized-Medicine-Report1.pdf.

[2] http://www.personalizedmedicinecoalition.org/Userfiles/PMC-Corporate/file/The-Personalized-Medicine-Report1.pdf.

[3] http://www.personalizedmedicinecoalition.org/Resources/Personalized__Medicine__at__FDA__An__Annual__Research__Report.

[4] http://www.personalizedmedicinecoalition.org/Resources/Personalized__Medicine__at__FDA__An__Annual__Research__Report.

[5] http://www.personalizedmedicinecoalition.org/Userfiles/PMC-Corporate/file/pmc-phrma-personalized-medicine-investment-21.pdf.

Aging (NIA) and the National Heart Lung and Blood Institute (NHIBI). An increase for NIH in fiscal year 2020 would protect its foundational role in the identification and development of personalized medicines.

II. SUSTAINING BASIC AND TRANSLATIONAL RESEARCH

Scientific discovery begins with basic research that gathers fundamental knowledge about the genetic basis of a disease and with translational research aimed at applying that knowledge to develop a treatment or cure. Basic research has contributed to the development of more than 130 personalized medicines on the market and available for patients as of 2017.[6] These include novel cancer immunotherapies that harness a patient's immune system to fight cancer.[7] This direction of treatment was possible thanks to the decades of basic research to understand how the immune system functions at the molecular level and the genetic characteristics of specific cancer types. NCI–MATCH, a phase 2 clinical trial, is now investigating whether targeted therapies for people whose tumors have certain gene mutations will be effective regardless of their cancer type. Patients from more than 1,100 cancer centers and community hospitals in every State have enrolled in the trial, and 62.5 percent of the first 6,000 patients enrolled had tumors other than the four most common cancers: breast, colorectal, non-small cell lung and prostate.[8]

Basic genomics research also offers opportunities beyond oncology, especially for rare diseases. Rare diseases affect an estimated 25 to 30 million Americans, and with advances in genomics, the molecular causes of 6,500 rare diseases have been identified. Sickle cell disease (SCD), a rare disease that affects approximately 100,000 people in the United States, is the first "molecular disease." The molecular basis of SCD was discovered decades ago but limited symptomatic treatments are available to patients. Novel genetic approaches are now providing hope for a SCD cure within 10 years. The NIH-launched Cure Sickle Cell Initiative is advancing the most promising next-generation SCD therapies and recently reported impressive results from one experimental gene therapy.[9]

There are other people living with highly prevalent diseases that are still in need of better treatments and a cure. The Alzheimer's Association estimates that 5.8 million Americans are living with Alzheimer's disease. Despite increasing numbers of Alzheimer's diagnosis, there are no treatments that can prevent or alter the course of the disease. Researchers are studying the genetic underpinnings of Alzheimer's disease to more fully understand its complexity. In 2018, an NIH-funded team of researchers reported that groups of genes associated with specific biological processes are "genetic hubs." These hubs are an important part of the disease process. This and other large studies involving the NIH will continue to allow for better prioritization of genes to target for treatment.[10]

III. ACCELERATING PERSONALIZED MEDICINE RESEARCH

The 21st Century Cures Act (Cures Act) provided support for important initiatives that will benefit personalized medicine. The first initiative, the All of Us™ Research Program, launched in May of 2018. All of Us is collecting genetic and health information from one million volunteers for a decades-long research project. By August 15, 2018, nearly 100,000 individuals enrolled as participants. Almost 50 percent of those individuals were from groups historically underrepresented in research, such as seniors, women, Hispanics and Latinos, African Americans, Asian Americans and members of the LGBTQ community.[11] This program is creating an invaluable biomedical data set that is inclusive of all Americans and will inform the development of new personalized medicines.

This year the NIH will begin a number of All of Us pilot projects aimed at getting new types of data for the research community and giving health information back to participants. For the research community, we expect to see pilots related to genotyping, whole genome sequencing, lab test assays, and wearable devices. All of Us will also begin a pilot on the responsible return of information to participants that will include their genomic information, genetic risk for disease, medication re-

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[6] http://www.personalizedmedicinecoalition.org/Userfiles/PMC-Corporate/file/The-Personalized-Medicine-Report1.pdf.

[7] https://officeofbudget.od.nih.gov/pdfs/FY19/br/Overview.pdf.

[8] https://www.nih.gov/news-events/news-releases/nci-match-precision-medicine-clinical-trial-releases-new-findings-strengthens-path-forward-targeted-cancer-therapies.

[9] https://directorsblog.nih.gov/2018/12/11/accelerating-cures-in-the-genomic-age-the-sickle-cell-example/.

[10] https://www.nia.nih.gov/news/data-sharing-uncovers-five-new-risk-genes-alzheimers-disease.

[11] https://www.nih.gov/about-nih/who-we-are/nih-director/testimony-prioritizing-cures-science-stewardship-national-institutes-health.

sponse, and visualization of basic electronic health record data. To further support All of Us participants, the NIH is developing a mobile app and other educational resources about developments in personalized medicine.[12]

The Cancer Moonshot is the second initiative supported by the Cures Act. It aims to transform the way cancer research is conducted. Because of funding for the Cancer Moonshot, NIH was able to issue 17 Funding Opportunity Announcements, including opportunities to support immunotherapy networks that promise to discover new cancer treatments for adults and children.[13] In addition to funding research aimed at improving cancer treatment, as part of the Cancer Moonshot the NCI was able to make a resource publicly available on thousands of inherited BRCA1 and BRCA2 gene variants. Certain inherited variants in these genes can increase the risk of breast, ovarian, and other cancers by varying degrees, whereas others are not associated with disease. Clinicians and patients need to know whether a given variant is likely to be disease-associated and how likely a variant is to cause cancer. Until the NIH's BRCA Exchange, the available data on the inherited BRCA variants were not aggregated in a comprehensive way or made available to clinicians, researchers, data scientists, patients, and patient advocates.[14]

The Cures Act authorizes funding for these initiatives through the Innovation Fund. The $2.5 billion increase requested by PMC in fiscal year 2020 would ensure that the $492 million authorized by the Cures Act this year would supplement the NIH's base budget as Congress intended and allow these important initiatives to continue.

IV. CONCLUSION

PMC appreciates the opportunity to highlight the NIH's importance to the continued success of personalized medicine. The subcommittee's support for a $2.5 billion increase over the NIH's program level funding in fiscal year 2019 will bring us closer to a future in which every patient benefits from an individualized approach to healthcare. PMC will gladly provide additional information on the programs described in our testimony upon request.

[This statement was submitted by Cynthia A. Bens, Senior Vice President, Public Policy, Personalized Medicine Coalition.]

PREPARED STATEMENT OF THE PHYSICAL SCIENCE EDUCATION POLICY COALITION

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

The Physical Science Education Policy Coalition (PSEPC) is a diverse group of scientific non-profit organizations that works to promote issues regarding all aspects of physical science education to benefit both students and teachers.

We urge you once again to reject the White House's budget proposal for the Department of Education to eliminate the following programs:

—Supporting Effective Instruction State Grants
—Student Support and Academic Enhancement Grants
—21st Century Community Learning Centers

Congress has authorized these programs to receive funding under Title II and Title IV of the Every Student Succeeds Act (ESSA). ESSA helps bolster our global competitiveness by allowing States the greatest opportunity to strengthen their own physical science and STEM education programs. Therefore, we urge you to fully fund these programs in fiscal year 2020 appropriations.

Congress has shown that it values high-quality physical science teachers and informal STEM learning by previously rejecting the White House's proposed huge cuts to these programs for fiscal year 2018 and 2019. Instead, Congress provided funding for them as part of the bipartisan omnibus spending bill (fiscal year 2018) and the Labor, Health and Human Services, Education and Related Agencies appropriations bill (fiscal year 2019).

These programs are vital for States to provide high-quality physical science and STEM education. The Supporting Effective Instruction State Grants (Title II–A) program allows States to fund grants for teacher preparation programs. There is a significant shortage of highly qualified middle and high school physics teachers. In

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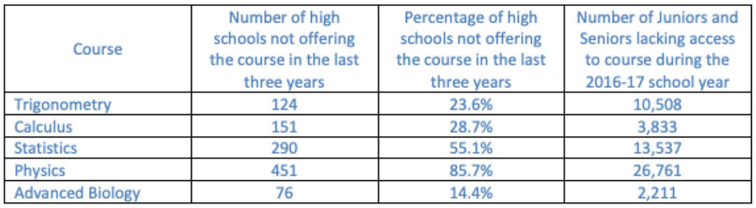
[12] https://allofus.nih.gov/sites/default/files/dish__new__year.docx.

[13] https://www.nih.gov/about-nih/who-we-are/nih-director/testimony-21st-century-cures-implementation-updates-fda-nih.

[14] https://www.nih.gov/news-events/news-releases/brca-exchange-aggregates-data-thousands-brca-variants-inform-understanding-cancer-risk.

a nationwide survey of teachers in U.S. high schools who taught at least one physics class, only 40 percent have major or minor in physics or physics education.[1] Title II–A funded teacher preparation programs train teachers to deliver robust, high-quality STEM education. The Student Support and Academic Enhancement Grants (Title IV–A) and the 21st Century Community Learning Centers (Title IV–B) gives States funding for out of school STEM programs to enhance learning.

The ESSA Consolidated State Plan published by the Missouri Department of Elementary and Secondary Education (MO–DESE) in 2018[2] states, “MO–DESE has a single area of critical need for State-level activities under Title IV, Part A, Subpart 1. A recent statewide analysis of advanced course offerings in mathematics and science indicated that a significant number of high schools do not offer, and consequently a significant number of students do not have access to, advanced coursework.” The table below presents data from the report that provides examples of courses that have limited availability to students. During the last 3 years, 451 high schools in Missouri—or 86 percent of all high schools in the State—have failed to offer a single physics course. This equated to more than 26,000 junior and senior students lacking access to a physics course during the 2016–17 school year.



Course	Number of high schools not offering the course in the last three years	Percentage of high schools not offering the course in the last three years	Number of Juniors and Seniors lacking access to course during the 2016-17 school year
Trigonometry	124	23.6%	10,508
Calculus	151	28.7%	3,833
Statistics	290	55.1%	13,537
Physics	451	85.7%	26,761
Advanced Biology	76	14.4%	2,211

According to the 2018 Oklahoma Educator Supply & Demand Report,[3] the overall number of educators employed in Oklahoma’s public schools who have certificates in math and science has consistently declined between 2012–13 and 2017–18. Certificates in math declined by 10 percent, and certificates in sciences drastically declined by 21 percent. Instead of loosening requirements for entry into the profession to solve this problem, the Oklahoma State Department of Education (OSDE) assembled a Teacher Shortage Task Force to implement changes that would strengthen the teacher pipeline, thereby bolstering recruitment and retention efforts in the State. The Oklahoma ESSA Consolidated State Plan[4] says, “The complete elimination of Title II, Part A funding would severely hamper the State’s ability to achieve its goal of reducing its need for emergency certified teachers. Title II, Part A dollars are critical to Oklahoma’s efforts to enhance meaningful professional development offerings, provide supports to teachers in implementing rigorous academic standards and equip instructional leaders who can support teachers and ultimately increase academic achievement for all students.”

A strong physical science background prepares students for success in their university courses and careers. Student success also depends upon them being taught by highly qualified teachers who have deep knowledge of physical science. We should all strive to ensure that our children receive the best education possible.

Thank you for your consideration. For additional information or to learn more about the Physical Science Education Policy Coalition please contact Dr. Bethany Johns from American Institute of Physics at bjohns@aip.org.

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[1] Who Teaches High School Physics?, https://www.aip.org/sites/default/files/statistics/highschool/hs-whoteaches-13.pdf.

[2] Every Student Succeeds Act, Missouri’s Consolidated State Plan, https://dese.mo.gov/sites/default/files/Missouri-Final-ESSA-Plan.pdf#page=62.

[3] 2018 Oklahoma Educator Supply & Demand Report, https://sde.ok.gov/sites/default/files/documents/files/Oklahoma%20Teacher%20Supply%20and%20Demand%20Report%202018%20February%20Update.pdf.

[4] Oklahoma ESSA Consolidated State Plan, https://www2.ed.gov/admins/lead/account/stateplan17/okconsolidatedstateplan.pdf.

DEPARTMENT OF EDUCATION

[selected programs, in millions]

Funding Line	Fiscal Year			
	2018 Enacted	2019 Enacted	2020 President's Budget Request	2020 PSEPC Request
Supporting Effective Instruction State Grants (Title II, Part A)	2,056	2,056	0	2,296
Student Support & Academic Enrichment Grants (Title IV, Part A)	1,100	1,170	0	1,600
21st Century Community Learning Centers (Title IV, Part B)	1,212	1,222	0	1,222

Endorsed by the following member organizations:

Acoustical Society of America (ASA)
American Association of Physics Teachers (AAPT)
American Astronomical Society (AAS)
American Institute of Physics (AIP)
American Physical Society (APS)
The Optical Society (OSA)

[This statement was submitted by Dr. Bethany R. Johns, American Institute of Physics, Physical Science Education Policy Coalition.]

Prepared Statement of the Physician Assistant Education Association

The Physician Assistant Education Association (PAEA), on behalf of the 243 accredited PA programs in the United States, is pleased to submit the following testimony in support of increased investment in Title VII health workforce programs under the Public Health Service Act in fiscal year 2020. At a time of both growing public health crises, including the national opioid epidemic, and looming provider shortages, Title VII programs have become increasingly critical to ensure continued access to high-quality care for patients. In alignment with our health professions education colleagues, we request a total of $690 million for both Title VII health professions and Title VIII nursing programs in fiscal year 2020. This level of Federal support will provide PA education, as well as our health professions peers, with needed investments to prepare the next generation of healthcare providers to care for all Americans.

THE ROLE OF PAS IN CARE DELIVERY IN RURAL AND MEDICALLY UNDERSERVED AREAS

Throughout our profession's history, PAs have been on the frontlines of healthcare delivery in the United States as critical components of the health workforce in rural and medically underserved areas. Through an intensive training process, PAs complete 1 year of classroom-based instruction followed by full-time clinical rotations in the fields of family and internal medicine, pediatrics, emergency medicine, obstetrics and gynecology, general surgery, and behavioral health, in addition to elective rotations. Our member programs graduated 8,336 PAs in 2017, with a plurality of graduates going on to serve in primary care practices.[1] As a result of both the origins of the profession as well as the emphasis on primary care during clinical rotations, PAs currently constitute a significant portion of the primary care workforce, with more 32,864 certified PAs currently practicing in primary care specialties.[2]

Clinical training site shortages have emerged as the preeminent barrier to program expansion. Fueled by health system consolidation and increasing demands on clinician time, among other factors, clinicians are less able to donate their clinical training expertise. The national clinical site shortage threatens to hinder PA workforce development at a time where an aging population and growing public health threats necessitate considerable workforce expansion. According to a recent PAEA Curriculum Report, 43.7 percent of PA programs now pay for clinical training sites,

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[1] Physician Assistant Education Association. (2018). By the Numbers: Program Report 33: Data from the 2017 Program Survey, Washington, DC: PAEA. doi: 10.17538/PR33.2018.

[2] National Commission on Certification of Physician Assistants. (2018). 2017 Statistical Profile of Certified Physician Assistants by Specialty. Johns Creek, GA: NCCPA. https://prodcmsstoragesa.blob.core.windows.net/uploads/files/2017StatisticalProfilebySpecialty.pdf

up from 21 percent 5 years ago, a cost which is ultimately borne by students in the form of increased tuition due to limited Federal support for PA clinical training.[3] To resolve this issue, PAEA urges the committee to support innovative policy interventions such as the Rural and Underserved PA Workforce Demonstration proposed in H.R. 1686, which would invest in PA clinical rotations in federally qualified health centers, rural health clinics, and critical access hospitals, thus addressing both the clinical site shortage and the issue of health workforce maldistribution.

THE OPIOID CRISIS: PA EDUCATION IS PART OF THE SOLUTION

In spite of the recent enactment of comprehensive legislation by Congress to address the national opioid epidemic, the number of opioid-related overdose deaths nationally has continued its dramatic rise. According to the National Institute on Drug Abuse, 47,600 people perished in 2017 as a result of opioid overdoses.[4] A critical component of an effective national response to the opioid epidemic is a well-trained behavioral health workforce equipped to ensure access to evidence-based therapies such as medication-assisted treatment (MAT). In 2018, PAEA partnered with the American Academy of Addiction Psychiatry in a SAMHSA-supported effort to integrate the training required to prescribe buprenorphine, a common office-based form of MAT, into the curricula of PA programs throughout the country. Through this Federal investment in PA education, PA graduates are beginning to enter the workforce prepared to apply for the waiver to prescribe buprenorphine, illustrating the valuable impact of existing Federal investments as well as the potential achievements made possible through new resources. Specifically, we encourage the committee to provide $25 million for the Substance Use Disorder Workforce Loan Repayment program authorized in the SUPPORT for Patients and Communities Act to incentivize our graduates to fully utilize this training following graduation. We further urge the committee to provide $10 million for the Mental and Substance Use Disorder Workforce Training Demonstration, which was authorized in the 21st Century Cures Act.

CLINICAL TRAINING SITES: NEW INVESTMENTS NEEDED

An additional component of a broader national response to the opioid epidemic must be improving both the availability and quality of clinical training sites. In a 2014 survey of PA programs, behavioral and mental health clinical training sites and preceptors were found to be the third most difficult to recruit.[5] Increased demand for providers with the skills necessary to treat OUD will be a growing source of pressure on the Nation's already limited supply of clinical training sites in primary care. Continuing support of Title VII health workforce programs as well as innovative new solutions such as the Rural and Underserved PA Workforce Demonstration remain crucial steps Congress can take to improve the capacity of PA programs to prepare practice-ready graduates.

EXISTING TITLE VII INVESTMENTS

Beyond the need for new investments to improve the availability of clinical rotations, and particularly behavioral health and primary care rotations in traditionally underserved settings, PAEA is strongly supportive of existing Title VII programs with a successful track record in training students. The Primary Care Training and Enhancement (PCTE) program, for example, provides PA programs with the resources necessary to integrate curricular innovations such as student-run medical clinics into their programs in order to direct more students to primary care following graduation. Recognizing the importance of a well-trained PA workforce in primary care, Congress enacted a 15 percent allocation requirement for PA education under the PCTE program. This funding floor has been an invaluable tool for stimulating innovation in PA primary care education—with demonstrable positive implications for student training and patient care. Citing the most recent outcomes data available as of fiscal year 2017, the Health Resources and Services Administration (HRSA) has reported that the PCTE program significantly exceeds targets both in the number of PAs graduating from funded programs (357 compared to a goal of

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[3] Physician Assistant Education Association, By the Numbers: Curriculum Report 3: Data from the 2017 Clinical Curriculum Survey. Washington, DC: PAEA, 2018. doi: 10.17538/CR3.2017.001.

[4] National Institute on Drug Abuse. (2019). Overdose Death Rates, Bethesda, MD: NIDA.

[5] Physician Assistant Education Association. (2014). 2014 PAEA Program Survey. Alexandria, VA: PAEA.

120 in fiscal year 2017) as well as those trained in and going on to practice in underserved areas.[6]

DIVERSITY AND CARE FOR UNDERSERVED POPULATIONS

As a core principle, PAEA believes that the delivery of high-quality care is dependent upon the development of a health workforce that reflects the communities it will serve. To this end, in addition to the innovation in primary care instruction made possible through PCTE grants, PAEA also strongly supports increased funding for Scholarships for Disadvantaged Students, the Health Careers Opportunity Program, and the National Health Service Corps Substance Use Disorder Workforce Loan Repayment Program. These programs have served to create a pipeline to PA education for diverse students while providing the incentives necessary for them to practice in underserved communities following graduation.

RECOMMENDATIONS FOR FISCAL YEAR 2020 APPROPRIATIONS

To facilitate continued innovation in PA education, PAEA urges the Subcommittee to reinforce its commitment to Title VII health workforce programs in fiscal year 2020. Along with our partners in the health professions, we support funding Title VII and Title VIII programs at a total level of $690 million for fiscal year 2020.

PAEA thanks the Subcommittee for its ongoing support of Title VII health workforce programs and their role in supporting PAs in extending access to care in rural and medically underserved areas. We look forward to the opportunity for continued engagement with the Subcommittee and its members in devising innovative solutions to the challenges facing health professions education.

[This statement was submitted by Jonathan Bowser, MS, PA-C, President, Physician Assistant Education Association.]

PREPARED STATEMENT OF THE PLANNED PARENTHOOD FEDERATION OF AMERICA

Dear Chairman Blunt and Ranking Member Murray,

Planned Parenthood is the Nation's leading women's healthcare provider and advocate and a trusted, nonprofit source of primary and preventive care for women, men, and young people in communities across the U.S. Every year, Planned Parenthood health centers provide affordable birth control, lifesaving cancer screenings, testing and treatment for sexually transmitted infections (STIs), and other essential care to nearly 2.4 million patients. As the largest sex educator in the country, Planned Parenthood provides reliable reproductive health information to 1.5 million young people and parents each year. Backed by more than 12 million supporters, Planned Parenthood works every day to defend access to healthcare and advance women's rights at home and abroad. Through our international arm, Planned Parenthood Global, we provide financial and technical support to over 100 innovative partners in 12 countries in Africa and Latin America for service delivery and advocacy to expand access to reproductive healthcare and empower people to lead healthier lives.

On behalf of Planned Parenthood Federation of America, I am writing to request you protect critical domestic and global reproductive health and family planning programs while increasing funding for key programmatic priorities. Continued investment in family planning programs will ensure women's access to essential primary and preventive healthcare services. These important programs have been effective at improving health outcomes; the U.S. is currently experiencing the lowest level of unintended pregnancy in 30 years and the lowest rate of abortion since Roe v. Wade was decided in 1973. Globally, the rate of unintended pregnancy has also declined, although progress remains uneven, and maternal mortality has decreased by over 40 percent over the past two decades.

This historic progress in women's health is in large part due to significant expansions of family planning services and the increased availability of more reliable forms of birth control. In the face of this evidence, the Trump-Pence Administration continues to issue budget proposals that would undermine and threaten to erode this important progress. Additional proposed and final rulemaking on a number of topics, including Title X and standards for the Affordable Care Act (ACA) marketplaces, amount to full-scale attacks on access to women's healthcare. This is particularly alarming for women of color in the United States, who continue to have less access to quality healthcare due to the intersections of structural racism, inequality,

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[6] Health Resources and Services Administration. (2019). Fiscal Year 2020 Congressional Budget Justification. Rockville, MD: HRSA.

sexism, classism, xenophobia, and other systemic barriers. Reinstatement of the global gag rule has begun to erode similar progress made abroad and the unprecedented expansion will magnify the well-documented harmful impacts of the policy on communities around the world. Attacks on domestic and global health programs only exacerbate existing health equity challenges and the effort to ensure that no one is left behind.

Therefore, as you prepare the fiscal year 2020 appropriations bills, Planned Parenthood respectfully requests that you protect and support funding for several key programs that will help improve health outcomes and combat disparities, including by:

—Funding the Title X Family Planning Program
—Funding STI Prevention
—Funding the Teen Pregnancy Prevention Program
—Eliminating harmful policy riders that limit access to abortion

Protect and increase funding for Title X—America's Family Planning Program

The Title X program serves more than four million low-income individuals annually at nearly 4,000 health centers located nationwide.[1] Title X services are highly effective—helping to prevent nearly one million unintended pregnancies each year.[2] In every State, women and men rely on Title X for basic primary and preventive healthcare and family planning services, including contraception services and counseling, cancer screenings, and STI testing and treatment. The Title X program not only meets the healthcare needs of millions of individuals, but research has consistently shown that it is cost-effective too. For every public dollar invested in family planning, approximately $7.09 is saved in Medicaid-related costs,[3] a savings to both Federal and State Governments.

Unfortunately, despite the proven benefits and savings, the Title X program has been severely undermined. Since fiscal year 2014, the program has been flat funded at $286.5 million, despite the fact that a 2016 report from researchers at the Centers for Disease Control and Prevention (CDC), the HHS Office of Population Affairs, and George Washington University estimated that the program would need $737 million annually to meet the needs of all low-income, uninsured women in the United States.

In addition to proposing flat funding for the program in their budget request, the Trump-Pence administration published a final rule in March 2019 that would negatively impact the Title X provider network and impose a domestic "gag rule" that prohibits Title X program providers from making patient referrals for abortion care, even when a patient makes a specific request. The rule eliminates a longstanding requirement that Title X providers offer a broad range of medically-approved contraception and imposes onerous and unreasonable physical and financial separation requirements for abortion-related activities.

The rule would require us to practice medicine against the trust of our patients and is, quite simply, unethical. For this reason, more than 100 public health and medical organizations, including the American Medical Association, National Hispanic Medical Association, and the American College of Obstetricians and Gynecologists, have publicly registered their opposition to this final rule.

The rule has been followed changes this Administration has already imposed via the Funding Opportunity Announcement (FOA) for the Title X program, including removing reference to Quality Family Planning recommendations, the national standard of clinical care for family planning services produced by CDC and the U.S. Office of Population Affairs. Similarly, the term "natural family planning"—a reference to fertility awareness methods like the rhythm method or calendar method—appears six times, but the term "Long Acting Reversible Contraceptives (LARC)," the most effective methods of birth control that have been growing in popularity, doesn't appear once.

Although the ACA made great strides in expanding insurance coverage, the Supreme Court's decision to make the Medicaid expansion optional for States has resulted in many low-income individuals remaining uninsured, creating a significant gap in coverage that Title X health centers are relied upon to fill. Recent data showing declines in overall ACA marketplace enrollment only reinforces the challenge we

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[1] Fowler, C. I., Gable, J., Wang, J., & Lasater, B. (2017, August). Family Planning Annual Report: 2016 national summary. Research Triangle Park, NC: RTI International.

[2] Frost JJ et al., Contraceptive Needs and Services, 2014 Update, New York: Guttmacher Institute, 2016, https://www.guttmacher.org/report/contraceptive-needs-and-services-2014-update.

[3] Guttmacher Institute. Frost, J., Sonfield, A., Zolna, M., and Finer, L. Return on Investment: A Fuller Assessment of the Benefits and Cost Savings of the US Publicly Funded Family Planning Program. 2014. https://www.guttmacher.org/pubs/journals/MQ-Frost__1468-0009.12080.pdf.

face to ensure all Americans have access to high-quality, affordable care. We ask that you protect this critical program and support the health of millions of Americans by providing $400 million in fiscal year 2020 for the Title X program.

Provide Funding for STI Prevention at the Centers for Disease Control (CDC)

Sexually-transmitted infections (STIs) continue to constitute a major public health problem. The CDC reports that almost 2.3 million cases of syphilis, chlamydia, and gonorrhea were diagnosed in the United States in 2017, highlighting the need for people to access sexual healthcare. This marked the fourth consecutive year of increases in the rates of these STIs. Screening and treatment for STIs—including HIV/AIDS, gonorrhea, and chlamydia—are an essential part of planning for a healthy pregnancy and healthy communities.

In fact, untreated chlamydia is a major public health issue and the leading cause of preventable infertility. Nearly 1.6 million cases of chlamydial infection were reported in 2016, a 4.7 percent increase since 2015.[4] Despite CDC recommendations for routine screening, many sexually active women are not being tested for chlamydia infection, in part because of limited resources for screening. Every $1 spent on chlamydia screening and prevention saves $12 in reduced costs from complications.[5] Funding for CDC's HIV/AIDS, STD, and TB prevention programs should be increased to $1.2 billion, with significant increases specifically directed to the STD program. Increasing funding for the CDC's STI prevention programs is a cost-effective public health investment that will improve the lives of women across the country.

Increase Funding for the Teen Pregnancy Prevention Program and DASH, Eliminate Harmful and Ineffective Abstinence-Only-Until-Marriage Programs

As the Nation's leading provider of sex education, Planned Parenthood is committed to helping teens stay healthy and safe. It is crucial that young people have access to sex education programs that give them knowledge and skills they need to prevent unintended pregnancies and sexually transmitted diseases to develop healthy relationships. The Teen Pregnancy Prevention Program (TPPP) and the CDC Division of Adolescent and School Health (DASH) fund evidence-based programs for youth that have been proven to reduce sexual risk behaviors, thus contributing to a myriad of improved health outcomes, including reductions in rates of teen pregnancy.

Teen pregnancy rates are declining in the U.S. and are at a historic low, but are still much higher than most of the industrialized world, yet 75 percent of pregnancies among 15–19 year olds are unintended and significant racial and ethnic disparities in these rates persist. Teen pregnancy accounts for $9.4 billion a year in cost to taxpayers. TPPP and the DASH program are cost effective ways to fund sex education for youth; these programs have reduced sexual risk behavior among young people, thus contributing to the reduction in teen pregnancy. Sex education has a proven track record of helping young people make responsible decisions that keep them safe and healthy. These programs enjoy vast public support because of their crucial role in providing the information and education that young people need to grow into healthy adults.

On the other hand, policies and programs aimed at promoting an abstinence-only-until-marriage (AOUM) approach, or so-called "sexual risk avoidance," are harmful. This Administration continues to stand up and fund these approach despite years of research that shows AOUM programs are ineffective and do not adequately provide young people with the knowledge and skills to avoid sexual risk behaviors. By excluding significant portions of comprehensive sexual education, AOUM methods can provide inaccurate and incomplete information and can intentionally shame young people, particularly LGBTQ students.

The administration has made it very clear that they would like to unravel the TPPP program. The Chief of Staff to the HHS Assistant Secretary of Health made the following statement on Ohio public radio: "we're hopeful that Congress will eliminate the Teen Pregnancy Prevention Program but if they choose not to then we have every intention to improve this program so that more young people are helped as a result."[6] In addition, on November 3, 2017, HHS announced a "new research and evaluation collaboration to support and improve teen pregnancy preven-

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[4] Centers for Disease Control and Prevention. Sexually Transmitted Disease Surveillance 2016. Atlanta: U.S. Department of Health and Human Services; 2017. Available at https://www.cdc.gov/std/stats16/chlamydia.htm.

[5] Centers for Disease Control and Prevention. Chlamydia Screening and Treatment Programs for Young Women. March 1997. http://www.cdc.gov/media/pressrel/chlamy1.htm.

[6] Valerie Huber, Chief of Staff to the Assistant Secretary for Health, All Sides with Ann Fisher, Ohio Public Radio, August 23, 2017.

tion and sexual risk avoidance programs." These actions by the administration continue to ignore the positive impacts of TPPP. Dismantling this high quality, evidence-based program is short-sighted and will harm hundreds of thousands of our most vulnerable youth by denying them high quality information and education that will help make healthy decisions about their futures.

Planned Parenthood urges appropriators to provide $130 million for TPPP, including $6.8 million for TPPP dedicated evaluation transfer authority, and to provide $50 million for DASH. Finally, funding should be eliminated for ineffective abstinence-only-until-marriage programs.

These three specific requests are supported by the Sex Ed Coalition, comprised of over 40 national organizations including Advocates for Youth, The AIDS Institute, Guttmacher Institute, Healthy Teen Network, Human Rights Campaign, National Coalition of STD Directors, National Family Planning & Reproductive Health Association, Planned Parenthood Federation of America, and the Sexuality Information and Education Council of the U.S. (SIECUS). The full list of coalition members is available upon request.

Eliminate Harmful Policies That Undermine Access to Abortion and Women's Health

Opponents of women's healthcare have long used the appropriations process to undermine women's access to comprehensive reproductive care, including access to safe and legal abortion. Through policy riders in bills under the jurisdiction of multiple subcommittees, opponents have limited access for women on Medicaid, women who work for the Federal Government, women in prison, and others, including women living in the District of Columbia, which is even prohibited from spending non-Federal funds on these services. We urge the Committee to eliminate all such bans on women's access to comprehensive care and to restore abortion access for women who have coverage through programs like Medicaid or the Federal Employee Health Benefits Program and direct services through the Indian Health Service and Federal Bureau of Prisons. In addition, the Committee should reject the multiple harmful new policy riders we have seen proposed in years past that would roll back progress for women, including proposals to "defund" Planned Parenthood; enact sweeping new religious refusal language allowing employers, insurers, and healthcare providers to deny others access to abortion; and others.

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PPFA issues these requests in the hopes that we can protect and build upon Federal investments to make quality reproductive healthcare affordable and accessible so that women and their families can lead healthier lives. We welcome the opportunity to discuss these requests with you or your staff. If you have questions about any of the above requests, please don't hesitate to contact me (jacqueline.ayers@ppfa.org). For more information about domestic funding priorities, please contact Jack Rayburn, Associate Director, Legislative Affairs (jack.rayburn@ppfa.org).

Sincerely.

[This statement was submitted by Jacqueline Ayers, Vice President, Public Policy and Government Affairs, Planned Parenthood Federation of America.]

PREPARED STATEMENT OF THE POLYCYSTIC KIDNEY DISEASE FOUNDATION

The PKD Foundation appreciates the opportunity to present our support for appropriating $41.6 billion in fiscal year 2020 for the National Institutes of Health (NIH). We also request that $2.165 billion be provided to the National Institute of Diabetes and Digestive Diseases and Kidney Disease (NIDDK), and that 10 percent of this be dedicated to PKD research. Lastly, we request that you recognize PKD in NIH's next list to Congress on updated research activities.

ABOUT PKD

There are two forms of polycystic kidney disease (PKD): automosal recessive PKD and autosomal dominant PKD.

Autosomal recessive polycystic kidney disease (ARPKD), is a rare genetic disease, affecting 1 in 20,000 live births. It is often life-threatening and can cause death shortly after birth. If both parents have the ARPKD gene, there is a 25 percent chance that each offspring will have the disease. There is no treatment and no cure for ARPKD, and only limited research currently taking place.

Autosomal dominant polycystic kidney disease (ADPKD or simply PKD) is a genetic disease that causes fluid-filled cysts to grow uncontrolled in the kidneys and can eventually lead to kidney failure. It is a painful disease that significantly impacts quality of life, causing a host of other issues including cysts in other organs such as the liver, chronic hypertension and increased risk for cerebral aneurysms. A parent with ADPKD has a 50 percent chance of passing it to each child. ADPKD occurs in 1 in 500 to 1,000 individuals, but many cases go undiagnosed. Over 600,000 Americans are suspected to have ADPKD.

PKD is the fourth leading cause of kidney failure with about 50 percent of PKD patients entering end stage renal disease in their 50's. Very few treatment options exist for PKD patients, and once their kidneys fail they must undergo dialysis or a kidney transplant. While these options are life-saving, they are both associated with excess morbidity and mortality. The very first and only treatment for PKD was approved in April 2018. This treatment, although groundbreaking, does not work for all PKD patients and comes with significant side effects that impact daily life. Having additional treatment options to preserve and extend native kidney function is clearly the best option, particularly because there are far more patients in need of a transplant than there are available kidneys. Research is the path to additional treatments that stop or slow the progression of the disease with the ultimate goal of keeping the kidneys from failing.

ABOUT THE PKD FOUNDATION

The PKD Foundation is the only organization in the U.S. solely dedicated to finding treatments and a cure for PKD. We do this through promoting programs of research, education, advocacy, support and awareness on a national level, along with direct services to local communities across the country. We are the largest private funder of PKD research. Since our founding in 1982, we have invested almost $50 million in basic and clinical research, nephrology fellowships and scientific meetings with a simple goal: to discover and deliver treatments and a cure for PKD.

OUR REQUEST

The PKD Foundation appreciates your interest in NIH research efforts and thanks Congress for increasing funds for the NIH over the past few years. NIH is intended to devote $29 million for PKD research in fiscal year 2019; actual spending amounts are no yet available. In fiscal year 2013, that figure was $40 million. Unfortunately, it is notable that PKD receives less funding from the NIH than other significantly less prevalent genetic diseases. It is also notable that, unlike non-renal diseases, Medicare pays for dialysis and care of PKD patients in end stage renal disease (ESRD) regardless of age. According to a 2015 GAO report, in 2013 Medicare spent about $11.7 billion on dialysis care for about 376,000 patients, some of whom had PKD. The cost of this care is significantly greater than Federal research support.

Although the NIH received a 5.4 percent budget increase in fiscal year 2019 ($2 billion over fiscal year 18 funding levels), research in the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) received just under a 2.8 percent increase. Yet, since fiscal year 2013 NIDDK funding for PKD research has fallen by about 27 percent. By having NIDDK invest more in PKD research, a significant proportion of the PKD population could be converted from recipients of Medicare-funded ESRD coverage into more productive citizens.

The Appropriations Committees have expressed interest in specific health research areas. In recent years, appropriations bills have requested NIH to provide Congress with an update for a large number of listed diseases, conditions or topics, and a description of the latest efforts ongoing and planned for the following fiscal year. Unfortunately, PKD was not listed in any of these requests.

PKD patients and advocates have two requests for Congress as it develops the fiscal year 2020 funding bill for NIH:

—Provide $2.165 billion for NIDDK and direct that 10 percent of the additional funds be used for increased PKD research.
—Provide $41.6 billion for NIH funding
—Include PKD in the next NIH update list in the final fiscal year 2020 appropriations bill.

[This statement was submitted by Alexis Denny, Director of Government Affairs, Polycystic Kidney Disease Foundation.]

PREPARED STATEMENT OF THE POPULATION ASSOCIATION OF AMERICA AND ASSOCIATION OF POPULATION CENTERS

Thank you, Chairman Blunt and Ranking Member Murray for this opportunity to express support for the National Institutes of Health (NIH), National Center for Health Statistics (NCHS), 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 2020, we urge the Subcommittee to adopt the following funding recommendations: $41.6 billion, NIH; $175 million, NCHS; $670 million, IES; and $655 million, BLS.

NATIONAL INSTITUTES OF HEALTH

Demography is the study of populations and how or why they change. A key component of the NIH mission is to support biomedical, social, and behavioral research that will improve the health of our population. The health of our population is fundamentally intertwined with the demography of our population. Recognizing the connection between health and demography, NIH supports population research programs primarily through the National Institute on Aging (NIA) and the National Institute of Child Health and Human Development (NICHD). As members of the Ad Hoc Group for Medical Research, PAA and APC recommend an appropriation of at least $41.6 billion for the NIH, a $2.5 billion increase over the NIH's program level funding in fiscal year 2019.

NATIONAL INSTITUTE ON AGING

By 2030, there will be 72 million Americans aged 65 and older. To inform the implications of our rapidly aging population, policymakers need objective, reliable data about the antecedents and impact of changing social, demographic, economic, health and well being characteristics of the older population.

The NIA Division of Behavioral and Social Research (BSR) is the primary source of Federal support for basic population aging research. In recent years, the BSR Division expanded its Alzheimer's disease research portfolio to include the population sciences. Some primary examples of this activity include enhanced collection of nationally representative data via the Health and Retirement Study to measure cognitive function to inform our understanding of national trends and differences. In addition to enhancing data collection, NIA developed a dementia care research agenda and added an Alzheimer's disease research component as part of the Roybal Centers of Translation Research in Behavioral and Social Sciences of Aging, Resource Centers for Minority Aging Research, and Demography and Economics of Aging Centers program.

In addition to continuing these activities in fiscal year 2020, with additional funding, the Division can pursue plans to renew and expand the Demography and Economics of Aging Centers Program as well as achieve its goals, which PAA and APC support, as articulated in its recently revised strategic directions document, Aging Well in the 21st Century: Strategic Directions for Research on Aging.

As members of the Friends of the National Institute of Aging, PAA and APC urge the Subcommittee to provide $450 million to support trans-NIH aging research initiatives in fiscal year 2020.

PAA and APC thank Chairman Blunt and Ranking Member Murray for their bipartisan support of the NIH. We hope you will continue to work together to provide the NIH with the level of funding, $41.6 billion, endorsed by the broader NIH advocacy community of which the PAA and APC are active members.

EUNICE KENNEDY SHRIVER NATIONAL INSTITUTE ON CHILD HEALTH AND HUMAN DEVELOPMENT

Since the Institute's inception in 1962, NICHD has had a clear mandate to support a robust research portfolio focusing on maternal and child health, the social determinants of health, and human development across the lifespan. Population research, now commonly termed "population science," is cited explicitly in the Institute's authorizing statute as a key tenant of the Institute's broader mandate. Accordingly, over the decades NICHD, specifically via its Population Dynamics Branch, has supported innovative and influential population science initiatives, including: (1) large-scale longitudinal surveys, with population representative samples, such as the National Longitudinal Survey of Adolescent Health and Fragile Families and Child Well Being Study; (2) a nationwide network of population science research and training centers; and, (3) numerous scientific research initiatives that have advanced our understanding of specific diseases and conditions, including obesity, autism, and maternal mortality, and, further, how socioeconomic and biological factors jointly determine human health.

In additional to supporting individual research grants and surveys, NICHD supports the Population Dynamics Centers Research Infrastructure Program. These highly productive centers, based at U.S. universities and private research institutions nationwide, have advanced U.S. science by fostering groundbreaking interdisciplinary research on human health and development, and increased the scientific pipeline by nurturing the careers of junior researchers. With additional funding in fiscal year 2020, the Institute will be able to maintain its strong commitment to these centers of research excellence as well as the rest of the Population Dynamics Branch's impressive research portfolio.

As members of the Friends of NICHD, PAA and APC request that NICHD receive $1.6 billion in fiscal year 2020, an increase of $94 million over fiscal year 2019.

NATIONAL CENTER FOR HEALTH STATISTICS

NCHS is the Nation's principal health statistics agency, providing data on the health of the U.S. population. NCHS funds and manages the National Vital Statistics System (NVSS), which contracts with the States to collect birth and death certificate information. NCHS also funds several complex large surveys to help data users understand the population's health, influences on health, and health outcomes. In the last year, critical research findings, including the number of deaths attributable to the opioid epidemic, decreased life expectancy in the U.S., decreased teen pregnancy, and the incidence of maternal and infant mortality, were informed by NCHS data. NCHS health data are an essential part of the Nation's statistical and public health infrastructure.

The rising costs of conducting surveys coupled with years of flat or near-flat funding has forced NCHS to focus most of its resources on sustaining high-quality data that communities across the country rely on to understand their health. However, as survey costs continue to rise, response rates decline, and our Nation's healthcare system becomes more complex, NCHS has not been able to invest in much-needed innovation and modernization that would allow it to produce better information more quickly and efficiently, while reducing the reporting burden on local data providers. With additional funding, NCHS could capitalize on opportunities surrounding advances in statistical methodology, big data, and computing by:

—Linking data reporting systems and better integrating electronic health records into NCHS' data production, allowing it to receive and process information more efficiently, reduce burden on data providers, and analyze and release statistics faster;

—Researching how to conduct its most complex surveys more efficiently, making surveys less costly to taxpayers and less burdensome on participants; and,

—Integrating machine learning into its analysis to spot trends in Americans' health earlier.

Any cuts below the agency's fiscal year 2019 level, which the Administration is proposing, would have a demonstrably negative effect on the agency's programs, survey data, and staff. For example, if NCHS's budget is reduced below its fiscal year 2019 funding level, NCHS will need to consider eliminating or radically altering one of its two seminal surveys: the National Health Interview Survey (NHIS)—the principal data source for studying demographic, socioeconomic, and behavioral differences in health and mortality outcomes since 1957—or the National Health and Nutrition Examination Survey (NHANES), which has assessed the health and nutritional status of adults and children in the United States since the early 1960s. Despite making marginal adjustments to accommodate years of budget cuts, including reducing sample size and delaying necessary survey innovations, the agency has stated it cannot responsibly sustain these surveys if its funding level dips below its fiscal year 2019 level, $160 million.

As members of the Friends of NCHS, PAA and APC urge the Subcommittee to reject the Administration's request ($155 million) and to provide NCHS with $175 million in fiscal year 2020. We are pleased that H.R. 2740, the fiscal year 2020 Labor, Health and Human Services and Education Appropriations bill passed by the House Appropriations Committee in May 2019, not only restores NCHS funding to its fiscal year 2019 level, but also includes a provision directing the Centers for Disease Control and Prevention to develop a plan for spending $100 million on data surveillance that includes NCHS. PAA and APC urge the subcommittee to adopt this provision.

BUREAU OF LABOR STATISTICS

The 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. Further, the field relies on unique BLS-supported surveys, such as the American Time Use Survey and National Longitudinal Surveys, to understand how work, unemployment, and retirement influence health and well-being outcomes across the lifespan.

As members of the Friends of Labor Statistics, PAA and APC are very grateful for $3 million increase that BLS received in fiscal year 2019. However, the agency is struggling to overcome years of insufficient support. Between fiscal year 2009 and fiscal year 2015, the purchasing power of BLS appropriations decreased every year. BLS needs a meaningful increase of funding in fiscal year 2020 to not only sustain current operations, but also to make much needed improvements in existing programs and surveys, including:

—Expanding the Job Openings and Labor Turnover Survey to improve timeliness and add industry detail and state level reports;
—Modernizing the Consumer Expenditure Survey to improve inflation statistics;
—Updating the Industrial Price and Import/Export program systems; and,
—Developing a new Survey of Employer-Provided Training.

Given the importance and unique nature of BLS data, and the adverse effect years of insufficient funding are having on the agency's ability to modernize and advance its core mission, we urge the Subcommittee to provide BLS with $655 million in fiscal year 2020, a $40 million increase over the agency's fiscal year 2019 funding level. It should be noted that the Administration requested $655 million for the BLS in fiscal year 2020 as well; however, the Administration's request stipulates that this increase be used entirely to pay for the physical relocation of the agency's headquarters by fiscal year 2024. PAA and APC encourage the Subcommittee to direct the BLS to prioritize any additional funding it may receive in fiscal year 2020 on support for programs and personnel. We are very pleased that the House Appropriations Committee recommended providing BLS with $675.8 million in fiscal year 2020. This funding level is a meaningful increase ($60.8 million more than the fiscal year 2019 enacted level and $20.8 million than the President's request) that would provide BLS with essential resources to revitalize the agency.

INSTITUTE OF EDUCATION SCIENCES

The Institute of Education Sciences (IES) is a semi-independent, nonpartisan branch of the U.S. Department of Education and plays a critical role in developing the research base for and examining the effectiveness of education programs and curricula. The National Center for Education Statistics (NCES) is the statistical arm of IES (as well as being one of the 13 Federal principal statistical agencies) and provides objective data, statistics, and reports on the condition of education in the United States. Population scientists rely on NCES-funded surveys to conduct research on the myriad topics, such as linkages between educational access and attainment to health outcomes of specific populations, economic well-being, incarceration rates and many other indicators.

PAA and APC, as members of the Friends of IES, urge the Subcommittee to provide the agency with $670 million in fiscal year 2020, a $54.5 million increase over the fiscal year 2019 funding level.

Thank you for considering our support for these agencies as the subcommittee drafts the fiscal year 2020 Labor, Health and Human Services and Education Appropriations bill.

[This statement was submitted by Mary Jo Hoeksema, Director, Government and Public Affairs, Population Association of America and Association of Population Centers.]

PREPARED STATEMENT OF POWER TO DECIDE

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

The undersigned organizations are dedicated to the health and success of youth in communities across the country, and as such we urge you to support the evidence-based Teen Pregnancy Prevention (TPP) Program. This competitive grant program has made an important contribution to building a body of evidence of what works when it comes to teen pregnancy prevention. The TPP Program is funded at $101 million for fiscal year 2019. As you work on the Senate LHHS bill for fiscal year 2020, we respectfully request that you include the following as the fiscal year 2020 House Appropriations Committee bill recently did:

—restore funding for the TPP Program to $110 million-its original funding level,
—provide language that protects the integrity of the TPP Program, and
—continue the $6.8 million investment in the evaluation of teen pregnancy prevention approaches.

Teen Pregnancy Prevention Program: Currently administered by the U.S. Department of Health and Human Services (HHS) Office of Adolescent Health (OAH),[1] the TPP Program is funding 81 competitive five-year grants (fiscal year 2015—fiscal year 2019) in a wide variety of communities and settings across the country, using evidence-based approaches. In addition, OAH recently awarded another 14 grants (fiscal year 2018—fiscal year 2019) to develop early research. The TPP Program has already made vital contributions to the growing body of knowledge of what works for whom and under what circumstance to prevent teen pregnancy. This resulted from a commitment to high-quality implementation, rigorous evaluation (primarily randomized control trials), innovation, and learning from results.

The teen pregnancy and teen birth rate have declined by an impressive 63 percent and 72 percent respectively since the early 1990s. There have been declines across all racial and ethnic groups, and in all 50 States. In addition, these declines have saved on public spending. A 2018 study found that in 2015 alone, the United States realized $4.4 billion dollars in savings due to the decline in the teen birth rate between 1991 and 2015.[2] Yet it is still the case that roughly one in four 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 helps address these disparities by targeting funds to youth and communities with the greatest needs.

Despite the progress that has been made, the United States still has the highest rate of teen pregnancies in the developed world-nearly 450,000 pregnancies to teens each year. At a time when the U.S. needs to become more competitive in the global economy, our teen pregnancy rates are still much higher than our trading partners and competitors, making it harder for many young people to achieve their goals. Only half of teen mothers obtain a high school diploma by age 22, and less than 2 percent will complete college by the time they turn 30. In addition, teen mothers and their infants are also at increased risk for poor health outcomes, such as preterm birth and low birth weight. Nevertheless, the unprecedented declines over the past two decades show that progress is possible.

The TPP Program is a pioneering government program that uses evidence, both as criteria for funding decisions and to rigorously evaluate results. Independent experts and members of Congress on both sides of the aisle recognize the value in evidence-based programs, as does the general public. For example, polling indicates that 85 percent of adults (75 percent of Republicans and 89 percent of Democrats) favor maintaining Federal funding for the TPP Program. Also, the September 2017 unanimously-agreed-to-report from the bipartisan Commission on Evidence-Based Policymaking—which was established by former House Speaker Paul Ryan and Senator Patty Murray—highlighted the TPP Program as an example of a Federal program developing increasingly rigorous portfolios of evidence.[3]

Yet since 2017, HHS has repeatedly sought to eliminate or undermine the TPP Program. This includes shortening the second cohort of five-year grants (fiscal year 2015—fiscal year 2019) to only 3 years, until grantees prevailed in 11 lawsuits filed in response to the grant shortening. Despite numerous concerns and repeated inquiries from Congress, attempts to fundamentally remake the program continue. For these reasons, we strongly urge appropriators to both fully fund the TPP Program and include language that protects the program from ongoing efforts to subvert congressional intent.

Evaluation of Teenage Pregnancy Prevention Approaches: As part of the growing bipartisan commitment to evidence-based policymaking there's a recognition of supporting high quality evaluation within Federal agencies. Congress has historically provided a modest amount of funding to evaluate teen pregnancy prevention approaches, including longitudinal evaluations. This funding, in conjunction with the

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[1] Murray, Patty (2019, April 2) Letter from Senator Murray to HHS Secretary Alex Azar regarding the restructuring of the Office of the Assistant Secretary of Health. Retrieved May 28, 2019 from www.help.senate.gov/imo/media/doc/Azar%20OASH%20Reorg%20Letter%20Final%204%202%2019—.pdf.

[2] Progress Pays Off. January 2018. Power to Decide. Retrieved May 28, 2019 from https://powertodecide.org/what-we-do/information/why-it-matters/progress-pays.

[3] CEP Final Report. September 2017. CEP Final Report: The Promise of Evidence-Based Policymaking. Retrieved May 28, 2019 from https://www.cep.gov/cep-final-report.html.

TPP Program, has contributed to deepening knowledge of what works to reduce teen pregnancy. This smart investment should be continued in fiscal year 2020.

We recognize that Congress faces tough budget decisions. In this context, fully funding and protecting the TPP Program is a modest but strategic investment by the Federal Government to address the Nation's still high rate of teen pregnancy. This investment also contributes to progress on a range of other critical issues that are important to Americans, from increasing high school and college completion, to strengthening the workforce, as well as improving maternal and infant health. We hope that you will stand with the groups below to protect this funding that will improve the lives of youth—today and for future generations—while also saving on public sector spending.

If you need additional information, please contact Rachel Fey, Director of Public Policy at Power to Decide at rfey@powertodecide.org.

Thank you for your consideration of these requests.

American Academy of Pediatrics
California Association of School Health Educators
Center for Latino Adolescent and Family Health
The Dibble Institute
EFFICACITY, LLC
Hawaii Youth Services Network
The Jacobs Institute of Women's Health
The Kirkpatrick Policy Group (OK)
Lee County Health Department (Dixon, IL)
Power to Decide
The Policy and Research Group
Project Vida Health Center (El Paso, TX)
Religious Coalition for Reproductive Choice
Results for America
SHIFT NC
Teen Pregnancy & Prevention Partnership (MO)
Wyman Center (MO)

Prepared Statement of Prevent Blindness

Prevent Blindness appreciates the opportunity to submit testimony to the Subcommittee and respectfully requests the following allocation and support in fiscal year 2020 to promote eye health and prevent eye disease and vision loss in the United States:

—$5,000,000 to restore and expand vision and eye health surveillance and public health intervention efforts at the Vision Health Initiative of the Centers for Disease Control and Prevention (CDC).

—$4,000,000 for the Glaucoma Project at CDC to allow the program to continue to improve glaucoma screening, referral, and treatment by reaching populations that experience the greatest disparity in access to glaucoma care.

INTRODUCTION AND OVERVIEW

Prevent Blindness is the Nation's leading nonprofit, voluntary organization committed to preventing blindness and preserving sight. Prevent Blindness represents millions of people of all ages across the country who live with low vision and vision-related eye diseases.

A Robert Wood Johnson Foundation study ranks eye disorders as the 5th leading chronic condition, requiring ongoing treatment and management over one's lifetime, among those aged 65 years and up and 7th across all age groups. The national cost of vision problems, including private and public payments for medical care, long-term care, patients' out-of-pocket costs, direct and indirect costs, and lost productivity and consequential lost tax revenue amounted to $145 billion in 2014, and is expected to increase to $274 billion by 2032 just as the baby boomer generation is projected to become Medicare-eligible. National expenditures on vision problems, as a result of an aging population and changes in demographics, are projected to reach $385 billion by 2032 and $717 billion by 2050. The proportion of these costs paid by government programs is projected to increase from 32.6 percent to 41.4 percent by 2050 as the last of the baby boom generation becomes eligible for Medicare. Vision impairment and eye disease often contribute to or are complicated by other serious health-related conditions including diabetes, falls and injuries related to falling, stroke, depression and social isolation, hearing impairment, or cognitive decline. Lack of mobility, independence, access to care and self-management of health conditions are all equally serious consequences of vision problems. With an aging population and a working adult population who faces a rise in chronic diseases that affect their vision and ability to maintain their own economic independence through sustained employment, now is the time to invest in our collective eye health.

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 promote eye health and prevent eye disease, vision loss, and blindness. We thank the Subcommittee members for working to ensure the VHI and Glaucoma Project at the CDC received additional investment in the fiscal year 2019 legislation. The increases we ask today are a critical first step to addressing the burden of vision impairment, and we urge Members to increase the VHI's funding level and maintain the fiscal year 2019 level for the Glaucoma Project at the CDC for fiscal year 2020. Vision loss is often preventable, but without the necessary funding to better understand eye conditions, expand access to care, develop treatment options, and expand public health systems and infrastructure to disseminate good science and prevention strategies, millions of Americans face the loss of independence, health, and their livelihoods.

VISION AND EYE HEALTH AT THE CDC: HELPING TO SAVE SIGHT AND SAVE MONEY

The Centers for Disease Control and Prevention's Vision Health Initiative (VHI) was established in 2005 to address the ongoing national vision impairment and eye disease burden through surveillance, public health research, and evidence-based public health interventions. The VHI relies on the most reliable surveillance and epidemiology tool available—CDC's National Health and Nutrition Examination Survey (NHANES)—to track State-level data on vision loss and eye disease, including variances across difference subgroups and demographics, and implement findings into evidence-based, strategic public health interventions at the State and community level. However, due to a severe and continued lack of resources allocated through Federal appropriations to the VHI over the past eight fiscal years (fiscal year 2011—fiscal year 2019), national prevalence estimates of vision impairment and eye disease are nearly 10 years old with the last use of the NHANES to collect vision and eye health data conducted between 2005 and 2008.

Without the resources to employ the NHANES, the VHI has leveraged existing national surveys to create estimations of our national vision and eye health burden through use of the Behavioral Risk Factor Surveillance System (BRFSS) and American Community Survey (ACS). However, these tools are limited due to variation in the questions being asked, data based on self-reported rates of severe vision loss and blindness and not eye disease or vision impairment, and the limited scope of data available. Additionally in 2015, the CDC funded a project to establish a national Vision and Eye Health Surveillance System (VEHSS) bringing together existing data sets on vision impairment and eye disease. This work translated into the foundation of a 2016 report from the National Academies of Sciences, Engineering, and Medicine, *Making Eye Health a Population Imperative: Vision for Tomorrow*.

The NASEM report specifically outlines the important role of the CDC's Vision Health Initiative in facilitating needed surveillance, public health research and interventions, and building State and local capacity to incorporate vision and eye health at the community level. Equipping the VHI with the resources needed to update national and State-level prevalence estimates of the most serious eye diseases and vision impairments is one of the report's top priorities. The work of the CDC's VHI must lead the efforts to align policy to slow the national growth of vision problems, saving both sight and dollars for Federal and State Governments, as well as private individuals and institutions.

Without adequate funding, the VHI has been unable to employ the NHANES, which is the most reliable tool available to collect data related to the national scope and burden of vision loss and eye disease. With at least $5 million appropriated to the VHI in fiscal year 2020, VHI can resume use of the NHANES to collect data on rates of diabetic retinopathy, glaucoma, and vision loss as well as determine rates of vision and eye examinations and measurements of visual acuity, screening tests, and visual functioning assessment to better determine where gaps in access and patient education exist. This data can bolster State capacity to respond to the needs of their population with collaborative interventions and targeted strategies to improve vision and eye health at the State, local, or systems level. This much-needed and overdue injection of capital can be used to deploy this information to State and local public health departments to get these strategies on the ground.

While updated national prevalence estimates of our vision and eye health burden are needed, what we do know is that at least 12 million Americans aged 40 and older (working age adults) have impaired vision. 1 million Americans are blind, 3 million Americans have uncorrectable vision impairment, and 8 million live with uncorrected refractive error. Diabetic eye disease, glaucoma, uncorrected refractive error, and age-related macular degeneration are the most common, yet most preventable, reasons why people lose their sight. With $5 million in renewed investments to the VHI to create change in the current system, these trends can be reversed.

GLAUCOMA PROJECT

As well, we ask the Committee to consider the CDC's work in improving glaucoma screening, referral, and treatment particularly for populations that face disparity in access to glaucoma care. Glaucoma is a leading cause of blindness for people aged 60 years and older. Glaucoma is often called the "thief of sight" because it shows no symptoms or noticeable vision loss in its early stages. Early detection and treatment is vital in glaucoma care because, by the time vision loss or other symptoms appear, permanent and irreversible damage to the eye has already occurred and lost vision cannot be restored. We ask the Committee to maintain funding for the Glaucoma project at the CDC so that the work may continue reaching high-risk populations with an emphasis on the need for early detection and monitoring of glaucoma.

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 2020 funding for the CDC Vision Health Initiative, CDC Glaucoma Project, and the MCHB National Center for Children's Vision and Eye Health. Please know that Prevent Blindness stands ready to work with the Subcommittee and other Members of Congress to advance policies that will prevent blindness and preserve sight.

[This statement was submitted by Jeff Todd, President & CEO, Prevent Blindness.]

PREPARED STATEMENT OF PROJECT CURE, INC.

Dear Subcommittee Members:

I am writing on behalf of Project Cure, Inc., a 501(c)(4) public advocacy group that promotes research into natural therapies for a variety of disease conditions and to enhance wellbeing. I am Michael Evers, Esq., a well-known leader in this arena for more than 30 years.

I first will provide some background information on the important role played by a small agency buried within the National Institutes of Health—The National Center for Complementary and Integrative Health (NCCIH).

Back in 1987, the American Medical Association (AMA) was found guilty of conspiring to destroy the chiropractic profession in the U.S. by operating a "Committee on Quackery" for more than 20 years whose goals were to first contain, and eventually eliminate chiropractic.[1] Tension between conventional medical doctors and those promoting "alternative medicine" was at an all-time high. Zealots calling themselves "quackbusters" openly collaborated with Federal and State agencies to impede efforts to legitimize acupuncture, chiropractic, naturopathy, and many other forms of "natural healing." The Food and Drug Administration (FDA), Federal Trade Commission (FTC), U.S. Postal Service, and the National Association of Attorneys General were all under the influence of these medical bigots, whose mission had morphed from containment of chiropractic to total annihilation of anything under the alternative medicine banner.

As a young attorney, and adopted son of H. Ray Evers, M.D., one of the leading holitic medical doctors calling for more openness and cooperation between the varied professions, I surveyed the controversy and concluded something had to happen at the Federal level to change the dynamics of this ongoing battle. In 1987 I was commissioned by the former Congressional Office of Technology Assessment (OTA) to prepare a report on the legal constraints facing physicians and patients who opt for cancer treatment alternatives outside conventional medicine. Although the report was focused on alternative cancer treatments, I addressed the broader question of how to bring alternative medicine into the mainstream. My recommendation: create

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[1] Wilk v. American Medical Ass'n, 671 F. Supp. 1465, N.D. Ill. 1987, affirmed 895 F.2d 352, 7th Cir. 1990.

an office somewhere in the Federal health complex to serve as a clearinghouse for evidence-based information about these alternative therapies.[2]

I began lobbying efforts aimed at Congress using simple, but effective, grassroots methods to promote greater awareness and acceptance of alternative medicine. Congress responded by creating the Office Alternative Medicine (OAM) within the National Institutes of Health (NIH) in 1991 and provided $2 million for its initial budget. OAM began to develop a baseline of information on CAM use in the U.S. In 1992 OAM officials conducted two groundbreaking CAM workshops in Chantilly, Virginia examining such issues as research infrastructure, research databases, and research methodologies.[3]

Since vitamins and herbal medicines are mainstays employed by many CAM practitioners, I next turned my attention to changing the way the FDA regulated those products. I served as national legislative director for the Nutritional Health Alliance, the industry-led coalition that lobbied for passage of the Dietary Supplement Health and Education Act (DSHEA). Congress enacted DSHEA in 1994, legally establishing the term "dietary supplement" and decreeing that FDA should regulate them like foods and not drugs.[4]

Meanwhile, Congress kept increasing the OAM budget from the original $2 million in 1991 to $19.5 million for fiscal year 1998. CAM was now a legitimate topic among a growing number of academics who were drawn to the new research dollars. Beginning in 1996, I led a 50-member coalition effort to convince Congress to elevate the OAM to a Center within NIH. Once again, Congress responded by establishing the National Center for Complementary and Alternative Medicine (NCCAM) in 1998 and appropriated $48.9 million to vastly expand its research funding capabilities. The following year, researchers from eight top medical schools across the country gathered to form the Consortium of Academic Health Centers for Integrative Medicine. Harvard, Stanford, Duke and others answered the call to conduct the badly needed research to find out which, if any, CAM products and treatments worked, and for what conditions.[5]

President Bill Clinton established the White House Commission on Complementary and Alternative Medicine in March 2000 to advise the Nation about how to go about conducting sound scientific research into this field so consumers can make informed decisions about which modalities to use and which to avoid. The Commission's 264-page report, issued in March 2002, addressed "the hopes and concerns of the American people and the professionals who serve them. It acknowledges and respects the American people's use of a variety of approaches to healthcare and emphasizes the need to use the tools of biomedical research to assess the perspectives and findings of a worldwide spectrum of approaches, techniques and systems of healing." The Commission underscored the fact that "Federal support is particularly needed for research on CAM products that are unpatentable and those that are frequently used by the public but unlikely to attract private research dollars."[6]

In September 2002, the Institute of Medicine was commissioned to convene another two-year study "to explore scientific, policy, and practice questions that arise from the significant and increasing use of CAM therapies by the American public." It's 337-page report published in 2005 thoroughly explored the emerging role CAM practices were playing in the U.S. and the challenges facing researchers who wanted to find answers using conventional scientific models.[7]

Funding for NCCAM continued to rise during these years until it reached $122.7 million in fiscal year 2006. In the years since we have seen real progress in our understanding of CAM. We've seen the term evolve from "alternative medicine," to "complementary medicine," to "integrative medicine," to the newest nomenclature—"integrative health." When rigorously conducted scientific studies demonstrate that

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[2] U.S. Congress, Office of Technology Assessment, Unconventional Cancer Treatments, OTA–H–405 (Washington, DC: U.S. Government Printing Office, September 1990.

[3] Workshop on Alternative Medicine, Alternative Medicine: Expanding Medical Horizons-A Report to the National Institutes of Health on Alternative Medical Systems and Practices in the United States (Bethesda: NIH, 1995).

[4] Dietary Supplement Health and Education Act of 1994, Public Law No. 103–417, 08 Stat. 4325 (1994).

[5] Consortium of Academic Health Centers for Integrative Medicine. Home page. Available at: https://imconsortium.org/home.html. Accessed June 3, 2019.

[6] White House Commission on Complementary and Alternative Medicine Policy. Final report, March 2002. Available at: http://govinfo.library.unt.edu/whccamp/pdfs/fr2002_document.pdf. Accessed June 3, 2019.

[7] Institute of Medicine. 2005. Complementary and Alternative Medicine in the United States. Washington, DC: The National Academies Press. Available at: https://doi.org/10.17226/11182. Accessed June 3, 2019.

a product or method works, it eventually gets "integrated" into mainstream medicine.

U.S. consumers are buying dietary supplements and visiting nonconventional healthcare practitioners in ever-increasing numbers. Sixty-four percent used supplements in 2008. By 2017 that number had risen to 76 percent.[8] NCCAM estimates 38 percent of Americans use some form of CAM.[9] The number of medical schools now in the Consortium has risen to 75.[10] But sadly, congressional appropriations for NCCAM have not kept up with the growing demand for answers. By the time 2016 rolled around, funding had risen to only $129.8 million. Last year funding increased to $146.5 million, but clearly more is needed.

They said "Build it and they will come." Well, we did build it. From the modest beginnings of the Office of Alternative Medicine in 1991 to today's National Center for Complementary and Integrative Health, Congress has overseen the growth and expansion of research into all sorts of questions that need answers. Nowhere is this more evident than with today's opioid crisis. Americans are in pain. A new analysis based on data from the 2012 National Health Interview Survey found that an estimated 25.3 million adults (11.2 percent) experience pain—that is, they had pain every day for the 3 months prior to the survey.[11] Unfortunately, all too many of these pain sufferers turn to opioid drugs for relief.

Pain is the most common reason Americans turn to CAM, and NCCIH is leading the way to conduct research into discovering whether there are effective alternatives to commonly prescribed pain medications. So far, the following have been identified as leading candidates:

—Acupuncture and yoga for back pain
—Acupuncture and tai chi for osteoarthritis of the knee
—Massage therapy for neck pain
—Relaxation techniques for severe headaches and migraine

Can these examples of nonpharmacological pain management regimens actually make a significant contribution to the Nation's opioid crisis? We will never know unless research is conducted to provide an answer. During its nearly 30 years within NIH, NCCIH has developed the talent and skills necessary to conduct rigorous scientific research that will produce reliable evidence to inform decisionmaking by the public, by healthcare professionals, and by health policymakers regarding the use and integration of complementary and integrative health approaches. Since most of these therapies and substances are already in the public domain and not eligible for patent protection like pharmaceuticals, public funding is essential to support such research.[12]

On behalf of Project Cure's thousands of supporters, as well as all Americans who want healthcare that is focused on the whole person and makes use of all appropriate therapeutic approaches, healthcare professionals, and disciplines to achieve optimal health and healing, I ask that Congress not only continue its support for NCCIH, but that it significantly increase funding in the 2020 Budget to $150 million or more.

Sincerely.

[This statement was submitted by Michael Evers, President, Project Cure, Inc.]

PREPARED STATEMENT OF THE PULMONARY HYPERTENSION ASSOCIATION

THE ASSOCIATIONS'S FY20 L-HHS APPROPRIATIONS RECOMMENDATIONS

—$7.8 billion in program funding for the Centers for Disease Control and Prevention (CDC)

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[8] 2017 Council for Responsible Nutrition Consumer Survey on Dietary Supplements, conducted Aug. 24–28 by Ipsos Public Affairs.

[9] Nahin RL, Barnes PM, Stussman BJ. Expenditures on complementary health approaches: United States, 2012. National Health Statistics Reports. Hyattsville, MD: National Center for Health Statistics. 2016.

[10] Consortium of Academic Health Centers for Integrative Medicine. Home page. Available at: https://imconsortium.org/home.html. Accessed June 3, 2019.

[11] Nahin RL. Estimates of pain prevalence and severity in adults: United States, 2012. Journal of Pain. 2015;16(8):769–780.

[12] White House Commission on Complementary and Alternative Medicine Policy. Final report, March 2002. Available at: http://govinfo.library.unt.edu/whccamp/pdfs/fr2002_document.pdf. Accessed June 3, 2019.

  - —$750,000 for a pulmonary hypertension awareness and early diagnosis campaign at CDC.
- —At least $41.6 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).

ABOUT PULMONARY HYPERTENSION

Pulmonary Hypertension (PH) is high blood pressure that occurs in the arteries of the lungs. It reflects the pressure the heart must apply to pump blood from the heart through the arteries of the lungs. As with a tangled hose, pressure builds up and backs up forcing the heart to work harder and less oxygen to reach the body. PH symptoms generally include fatigue, dizziness and shortness of breath with the severity of the disease correlating with its progression. If left undiagnosed or untreated it can lead to heart failure and death. In recent years, innovative treatment options have been developed and approved for PH. The effectiveness of current treatment options depends on accurate diagnosis and early intervention.

ABOUT PHA

Headquartered in Silver Spring, MD., the Pulmonary Hypertension Association (PHA) is the country's leading PH organization. PHA's mission is to extend and improve the lives of those affected by PH. PHA achieves this by connecting and working together with the entire PH community of patients, families, healthcare professionals and researchers. The organization supports more than 200 patient support groups; a robust national continuing medical education program; a PH clinical program accreditation initiative; and a national observational patient registry.

HEALTH RESOURCES AND SERVICES ADMINISTRATION

Due to the serious and life-threatening nature of PH, it is common for patients to face drastic health interventions, including heart-lung transplantation. To ensure HRSA can continue to make improvements in donor lists and donor-matching please provide HRSA with $8.56 billion in discretionary budget authority in fiscal year 2020.

CENTERS FOR DISEASE CONTROL AND PREVENTION

Please provide $750,000 for a PH Program at the Centers for Disease Control and Prevention's (CDC). PH patients are often not diagnosed for many years until the condition has reached a catastrophic stage. Considering the availability of effective therapies for early-stage PH, a CDC program focusing on education, awareness, and epidemiology activities that promote early and accurate diagnosis of PH would not only save countless lives but save the American healthcare system from spending on avoidable, negative medical outcomes.

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 pulmonary arterial hypertension (PAH). Patients with advanced PH cannot benefit as greatly from available therapies and often face dramatic and costly medical interventions, including 24-hour IV infused medication, increased risk for hospitalization and in some cases heart-lung transplantation. Such an effort would serve to complement PHA's own programs that support education, awareness, and epidemiological activities to promote early and accurate diagnosis and quality care for individuals with 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.

NATIONAL INSTITUTES OF HEALTH

Please provide NIH with meaningful increases—including at least $41.6 billion in program funding in fiscal year 2020—to facilitate expansion of the PH research portfolio so we can continue to improve diagnosis and treatment. NHLBI and PHA have partnered on a groundbreaking clinical study, the Redefining Pulmonary Hypertension through Pulmonary Vascular Disease Phenomics (PVDOMICS) program (RFA-HL-14-027 and RFA-HL-14-030). By collecting information from one thousand participants with various types of PH, and 500 participants without or at risk for PH, PVDOMICS hopes to find new similarities and differences between the current WHO classifications of PH, which could be a major step in learning about the disease and advancing patient care. This research is intended to lead to identification of both endophenotypes of lung vascular disease and biomarkers of disease that may be useful for early diagnosis or for assessment of interventions to prevent or treat PH.

PROPER HEALTH COVERAGE AND ACCESS

The PH community is concerned that the Centers for Medicare and Medicaid Services (CMS) is allowing insurance payers to refuse to accept charitable copay and premium assistance on behalf of patients with complex, chronic and life-threatening conditions like PH. Because of breakthroughs in research, PH patients are able to utilize life-sustaining treatments that allow them to manage this potential fatal condition and lead relatively normal lives. When patients are denied access to financial assistance they are forced to choose between necessities, between dramatically shortening their lives by giving up medication in order to afford housing and food or continuing medication while starting their families on the road to bankruptcy We aware of the Subcommittee's continued requests for an explanation of this practice targeting rare disease patients. We ask that this Subcommittee once again ask CMS to explain this decisions and also encourage them to fix this problem that is greatly affecting the rare disease community.

PATIENT PERSPECTIVES

Before developing pulmonary hypertension, Doug was an architect specializing in historic preservation. Being an architect was the only thing he had ever wanted to do "when he grew up." Doug spent 2 years seeking an accurate diagnosis for his shortness of breath. During that time, he was misdiagnosed with depression, sleep apnea, altitude sickness and asthma. Ultimately Doug was diagnosed and treated, however he had to give up his career due to his PH.

Edith is Medicare recipient in her 70s who was diagnosed with pulmonary hypertension about 5 years ago. Edith says, "If I didn't have the medication I wouldn't be around. I would have passed away. And I don't want to do that because I have great grandchildren and I want to see them grow up." Edith's husband adds, "without her medications she cannot breathe. Without these drugs I would lose my wife in a day."

Aine's parents heard over and over that there was nothing wrong with their daughter. When they relayed her shortness of breath with exertion to physicians they were ignored or told she was just anxious. Aine was 8 years-old when she died.

Thank you again for your consideration of the PH community's priorities as you develop the fiscal year 2020 L-HHS Appropriations bill.

PREPARED STATEMENT OF REFUGEE COUNCIL USA

Chairman Blunt, Ranking Member Murray, and members of the subcommittee, thank you for this opportunity to submit these funding and oversight recommendations for fiscal year 2020 on behalf of the 25-member organizations of Refugee Council USA (RCUSA).[1] Our coalition is dedicated to refugee protection, welcome, and integration, representing the interests of refugees, refugee families, and volunteers and community members across the country who support refugees and resettlement. RCUSA recommends fiscal year 2020 funding levels of $2,565,201,000 for the Department of Health and Human Services' Refugee and Entrant Assistance (REA) account.

The REA account funds the Office of Refugee Resettlement (ORR) within the Administration of Children and Families (ACF). ORR funding provides critical Federal investments in the States and local communities that welcome refugees and is a crucial component[2] of fostering refugee integration and paving the way for the eco-

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[1] A list of RCUSA member organizations can be viewed at RCUSA.org.

[2] The initial component of welcome comes through the Reception and Placement Program, administered through the Bureau of Population, Refugees, and Migration (PRM) of the State Department in collaboration with the nine agencies and their affiliates.

nomic benefits that refugees provide to communities. In addition to new arrivals, ORR funding provides essential services to newly arrived refugees, as well as refugees that have already been resettled to the U.S. Besides refugees, ORR serves 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.

When a refugee arrives in the U.S., he or she is supported by one of nine voluntary nonprofit resettlement agencies. Through local affiliates across the country, the agencies help the newcomers with community orientation, English learning, school enrollment for children, and finding employment. With this crucial ORR support, refugees are not only able to support themselves and their families but they also become contributors to their new communities, integrating with and bringing innovation to our neighborhoods and communities. The following highlights critical programs within the REA account, but is not exhaustive:

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 secure early employment and become self-sufficient within 6 months without needing to access Federal or State assistance programs. The program leverages public funds with private donations at a 2:1 ratio, with nongovernmental agencies working hand-in-hand with local communities to match Federal Government contributions with private resources.

Refugee Support Services (RSS)

In fiscal year 2018, the Administration merged the administration of Refugee Social Services, Refugee Health Promotion, and Targeted Assistance into one new program, Refugee Support Services. RSS supports initial employability services and other integration services that address initial barriers to employment. It is provided to States and non-profit organizations based on formula pertaining to anticipated refugee and other arrivals and based on competitive grants. Additionally, school impact funding, provided through a formula in the RSS program, supports school districts with the funds necessary for activities for refugee children, like English language training, that will lead to their effective integration and education. RCUSA urges that RSS remain at at least the fiscal year 2019 enacted level.

Survivors of Trafficking

Since the passage of the Trafficking Victims Protection Act in 2000, victims of human trafficking have received case management services through HHS's partnership with NGO providers, including assistance obtaining and referrals to medical and psychological treatment, housing, educational programs, life skills development, legal services, and other assistance. Funding is also utilized to promote public awareness, training, and coalition building to raise awareness about human trafficking among law enforcement, social services, medical staff, and other potential first responders, in addition to other faith-based and community groups. These grants are crucial to providing victims, including children, integrative aid and services once they have been identified as a victim of trafficking. Increasing funding to $20 million for both the domestic and foreign-born survivor accounts is requested to adequately serve trafficking survivors. This funding is critical due to the successful increases in victim identification efforts. In fact, there has been an 843 percent increase in the number of foreign-born individuals served by the program from 2003 to fiscal year 2016.

Survivors of Torture

The Torture Victims Relief Act authorizes funding for domestic programs that address the long-term impacts of torture on survivors and their families. Effective rehabilitation programs address a survivor's physical, psychological, legal and social needs to reduce their suffering as quickly as possible. RCUSA's proposed $28 million for torture survivor assistance reflects that many treatment programs have long wait lists, and that—at current funding levels—demand will continue to exceed availability as programs serve not only refugees, but also (and in some cases predominantly) asylees and asylum seekers.

Unaccompanied Children (UC)

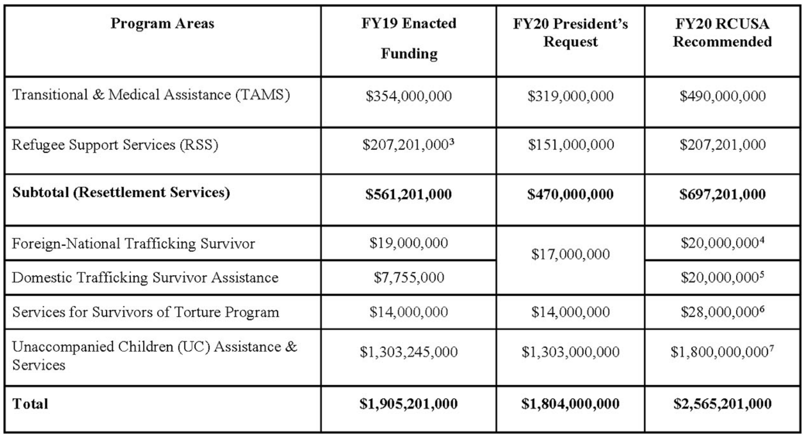
ORR provides children in its care with food, shelter, and clothing as well as educational, medical, mental health, and case management services. For a limited number of children, ORR provides family reunification services by social service providers; specifically, “home studies” to help ensure children are released into safe placements and “post-release services” to facilitate family and community integration after reunification. Family reunification services are an important means of assuring that children are not released to situations of abuse, neglect, or human trafficking. They also facilitate the continued well-being and adjustment of the children after reunification, including helping families to understand the child’s legal obligations and providing support to the families themselves as the children are integrated into their new communities. These practices not only promote child safety, but they can help reduce the need for involvement with the public child welfare system post-release. RCUSA supports baseline funding of at least $1,800,000,000 for the UC line item, with an emphasis on expanded funding for programs that promote successful family reunification and stability, which serve the best interests of the children. RCUSA also supports the expansion of permanent bed capacity.

ORR Contingency Fund

Many times in the last decade, ORR has had to reprogram funds from within ORR or the LHHS Secretary has transferred in funds from outside ORR to maintain vital services for refugees, unaccompanied children, and other populations of concern. For example, this occurred in 2012 ($115 million), in 2014 ($94 million), in 2018 ($446 million), and already this year ($385 million). These major shortfalls in the last decade demonstrate that ORR and the vulnerable populations that it serves need stronger financial footing. To avoid future reprogramming and greater financial stability, RCUSA supports the President’s request for a $2,000,000,000 UC contingency fund for use over 3 years and urges Congress to reserve $100 million of that contingency fund for all populations served by ORR.

In closing, RCUSA urges Congress to adopt the funding levels detailed below and to urge the Administration to maintain and adequately fund a robust national and local refugee resettlement network in support of the aforementioned goals. Thank you for considering our funding recommendations for fiscal year 2020.

FY 2020 Refugee and Entrant Assistance (REA) Account



Program Areas	FY19 Enacted Funding	FY20 President’s Request	FY20 RCUSA Recommended
Transitional & Medical Assistance (TAMS)	$354,000,000	$319,000,000	$490,000,000
Refugee Support Services (RSS)	$207,201,000[3]	$151,000,000	$207,201,000
Subtotal (Resettlement Services)	**$561,201,000**	**$470,000,000**	**$697,201,000**
Foreign-National Trafficking Survivor	$19,000,000	$17,000,000	$20,000,000[4]
Domestic Trafficking Survivor Assistance	$7,755,000		$20,000,000[5]
Services for Survivors of Torture Program	$14,000,000	$14,000,000	$28,000,000[6]
Unaccompanied Children (UC) Assistance & Services	$1,303,245,000	$1,303,000,000	$1,800,000,000[7]
Total	**$1,905,201,000**	**$1,804,000,000**	**$2,565,201,000**

[3] In fiscal year 2018 the Administration merged the administration of Refugee Social Services and Targeted Assistance into one new program, Refugee Support Services; Congress has not allocated less than $200 million cumulatively for these three programs in at least 15 years, not even taking inflation into account. Congress also continues to require funding for the Refugee Health Promotion program and ORR is providing it as an RSS set aside. The fiscal year 2019 Senate report indicates that in fiscal year 2018 the Committee accepted the administration’s proposal to combine all three programs but continues to expect that activities previously funded under these three lines will continue at the same level as before the consolidation.

[4] An increase is requested to serve trafficking survivors, given the 962 percent increase in the number of victims identified and certified in need of services since 2002, based on the 2002 ORR report to Congress and the 2016 Trafficking in Persons (TIP) report.

[5] See #2.

[6] RCUSA commends as a step in the right direction the $3.265 million increase in fiscal year 2019 to aid victims of torture, and yet the services gap remains extraordinary. Approximately 44 percent of the program’s beneficiaries-refugees, asylees and asylum seekers-are torture survivors. Even with the increased appropriation many programs have long wait lists and torture survivor populations across the country have no access to services at all. A $28,000,000 appro-

priation at least would likely match the funding necessary to rebuild the lives of those survivors who will be admitted permanently to the U.S. in fiscal year 2020.

[7] RCUSA urges funding at a level inclusive of both the fiscal year 2018 enacted amount and the total transferred to accommodate UC expenditures during fiscal year 2018 and in acknowledgement of the $385 million fiscal year 2019 transfer. RCUSA also supports continued funding for expansion of permanent bed capacity and increased family reunification services.

[This statement was submitted by Lacy Broemel, Refugee and Immigration Policy Advisor, The Episcopal Church, Refugee Council USA.]

PREPARED STATEMENT OF THE RESEARCH WORK GROUP

On behalf of the Federal AIDS Policy Partnership's Research Working Group, we thank Chairman Senator Graham, Ranking Member Senator Leahy and members of the Committee, for the opportunity to submit testimony to the Senate LHHS Subcommittee on fiscal year 2020 Appropriations for the National Institutes of Health (NIH) in regards to protecting, strengthening, and expanding our Nation's HIV/AIDS research agenda. The Research Work Group (RWG) of the Federal AIDS Policy Partnership (FAPP) is a coalition of more than 60 national and local HIV/AIDS research advocates, patient, clinicians and scientists from across the country. Our goal is to advance and support U.S. leadership to accelerate progress in the field of HIV/AIDS research. The FAPP RWG urges the subcommittee to build on the momentum of the House LHHS subcommittee request of $149 million increase for HIV research by recommending a fiscal year 2020 budget request level of at least $41.6 billion for the NIH, and ask that at least $3.450 billion be allocated for HIV research at the NIH in fiscal year 2020.

Public investments in health research via NIH have paid enormous dividends in the health and wellbeing of people in the U.S. and around the world, particularly for people living with, or vulnerable to, HIV. NIH funded AIDS research has supported innovative basic science for better drug therapies, evidence-based behavioral and biomedical prevention interventions which have saved and improved the lives of millions. NIH funding has contributed to over 210 approvals for a range of novel therapeutics between 2010 through 2016, with new antinfectives for HIV and HCV receiving the second largest fraction of those approvals. Additionally, NIH support was crucial in the development of pre-exposure prophlaxis (PrEP), a significant and groundbreaking HIV prevention tool that is upwards of 99 percent effective in preventing sexual transmission.

These developments were made possible through the U.S. government's strong support for NIH's HIV research portfolio, and hold great promise for significantly reducing HIV infection rates and providing more effective treatments for those living with HIV/AIDS in the coming decade. Despite such advances, there remain 1.1 million HIV people living with HIV in the U.S. in 2015. Each year this number increases. In 2017, 38,739 people in the U.S. received an HIV diagnosis. HIV research advances at the NIH hold the potential to end the AIDS epidemic, as well as update prevention approaches and improve outcomes along the treatment cascade—a cornerstone of the Trump Administration's recently announced initative to End the HIV Epidemic in the U.S. The fiscal year 2020 President's Budget has proposed Ending the HIV Epidemic: A Plan for America to reduce new infections by 75 percent in the next 5 years and by 90 percent in the next 10 years, averting more than 250,000 HIV infections in that span. Yet, the administration's fiscal year 2020 budget proposal ignores these significant contributions made by NIH and the need for a strong HIV/AIDS research agenda in the End the HIV Epidemic intiative with deep cuts in funding made to the Office of AIDS Research (OAR) that places current studies, including for a vaccine and a cure for HIV, in peril.

The fiscal year 2020 President's Budget request for the NIH HIV research program at OAR is $2,621.2 million, a decrease of $423.9 million or 13.9 percent compared to the fiscal year 2019 levels. The proposal includes substantial cuts (see table below) to HIV research into prevention, cure and HIV aging research. In particular, our Nation's research agenda in pursuit of a cure for HIV is under significant threat in the budget proposal, despite being the smallest part of the overall OAR budget. Scientific progress on cure and vaccine research remains steady and iterative, and cutting research funding at this juncture will only lengthen the time horizons or completely impede these studies from realizing the potential of these investments. To truly achieve an end to the HIV epidemic, we need a vaccine and cure alongside our current slate of therapeutics and prevention modalities. More importantly, investment in these critical areas is necessary to "finish the job" and cap the incredible progress that has been made to date thanks to Federal Government spending on HIV/AIDS research. In sum, these cuts would do harm to the HIV research agenda and the health of people living with HIV. We urge the subcommittee to reject these cuts.

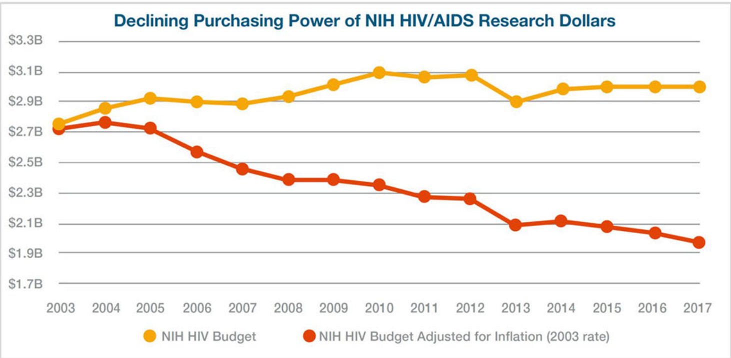
Table: NATIONAL INSTITUTES OF HEALTH Office of AIDS Research
Budget Authority by Activity (Dollars in Thousands)

Overarching Priorities	**FY 2016 Actual**	**FY 2017 Actual**	**FY 2018 Actual**[1]	**FY 2019 Enacted Level**	**FY 2020 President's Budget**	**FY 2020 +/- FY 2019**	**FY 2020 President's Budget % Reduction**
Reducing Incidence of HIV/AIDS	$732,003	$687,495	$714,553	$741,203	$634,517	-$106,686	-14.4%
Next Generation HIV Therapies	360,085	362,820	364,484	369,680	322,611	-$47,069	-12.7%
Research Toward a Cure[2]	108,337	170,375	175,757	190,735	159,384	-$31,351	-16.4%
HIV-associated Comorbidities, Coinfections, and Complications	614,090	556,608	517,884	537,435	469,998	-$67,437	-12.5%
Crosscutting	1,185,546	1,222,763	1,222,703	1,206,008	1,034,679	-$171,329	-14.2%
Total	**$3,000,061**	**$3,000,061**	**$2,995,381**	**$3,045,061**	**$2,621,189**	**-$423,872**	**-13.9%**

[1] Reflects effects of Secretary's transfer.

[2] Beginning in FY 2017, Research Toward a Cure for HIV/AIDS became a separate activity. Dollars for Research Toward a Cure for HIV/AIDS were previously included within other science areas, such as Next Generation Therapies, Crosscutting--Basic Research, and Reducing Incidence of HIV/AIDS. The FY 2016 amount is a comparable budget figure.

Furthermore, since 2003, funding for the NIH HIV research has failed to keep up with our existing research needs—damaging the success rate of approved grants and leaving very little money to fund promising new research—despite increases to the overall NIH budget. The real value of the increases prior to 2003 has been precipitously reduced because of the relatively higher inflation rate for the cost of research and development activities undertaken by NIH. According to the Biomedical Research and Development Price Index—which calculates how much the NIH budget must change each year to maintain purchasing power—between fiscal year 2003 and fiscal year 2017, the NIH budget in constant dollars according to BRDI will have declined by more than a third. The cuts proposed in President's budget only further widens the gap, in which even larger funding increases would be required to make up the value in research dollars lost.



Investment by the NIH has transformed the HIV epidemic from a terrible, untreatable disease to a chronic condition that can be managed through once-a-day drug regimens. Now is the time to increase investment for the NIH to finish the job and end the HIV epidemic through strategic, science-based interventions. Increasing the NIH's HIV research budget yields significant scientific gains, both for HIV and other diseases, produces economic benefits for our Nation's workforce, and enhances community engagement in research. NIH funding of HIV/AIDS research provides an example of innovation at work where investment in basic and translational research, working in partnership with industry and community, can move quickly to develop solutions. NIH investments in HIV/AIDS research also add value by seeding ideas later taken up in industry partnerships and creating innovation incubators for important medical advances which have significant health impact. Major advances over the last few years in HIV treatment and prevention demonstrate that adequately resourced NIH programs can transform our lives. Federal support for HIV/AIDS research has also led to new treatments for other diseases, including cancer, heart disease, Alzheimer's, hepatitis, osteoporosis and a wide range of autoimmune disorders.

Robust funding for NIH overall enables research universities to pursue scientific opportunity, advance public health, and create jobs and economic growth. In every State across the country, the NIH supports research at hospitals, universities, private enterprises and medical schools. This includes the creation of jobs that will be essential to future discovery. Sustained investment is also essential to train the next generation of scientists and prepare them to make tomorrow's HIV discoveries. NIH funding puts approximately 300,000 scientists to work at research institutions across the country. According to NIH, each of its research grants creates or sustains six to eight jobs and NIH supported research grants and technology transfers have resulted in the creation of thousands of new independent private sector companies. Strong, sustained NIH funding is a critical national priority that will foster better health and economic revitalization.

The race to find better treatments and a cure for cancer, Alzheimer's, heart disease, HIV/AIDS, and other diseases, and for controlling global epidemics like AIDS, tuberculosis and malaria, all depend on a robust long-term investment strategy for health research at NIH. There can be no innovation without reliable and adequate research funding. Tomorrow's scientific and medical breakthroughs depend on your vision, leadership and commitment towards robust NIH funding this year. Congress should ensure the Nation does not delay vital HIV/AIDS research progress. We must protect HIV/AIDS research funding to sustain research capacity and maintain our worldwide leadership in HIV/AIDS research and innovation.

To that end, we urge the subcommittee to consider a needed increase to the overall fiscal year 2020 budget request level of at least $41.6 billion for the National Institutes of Health (NIH) consistent with the request of the Ad Hoc Group for Medical Research. We also urge the Senate subcommittee to follow the House LHHS subcommittee to match or exceed their fiscal year 2020 recommendation of $149 million in increased funding for HIV research. While this increase gets us closer to meeting the recent Trans-NIH AIDS Research By-Pass Budget Estimate for fiscal year 2019, we ask the committee that at least $3.450 billion be allocated for HIV research at the NIH in fiscal year 2020, an increase of $450 million. We also urge the subcommittee to consider approaches to ensure HIV research budget receives increases alongside important and intersecting biomedical research at NIH. The fiscal year 2020 President's Budget request includes reallocation of $6 million in existing Centers for AIDS Research (CFAR) funding to support this initiative. We believe that CFARs are suited well to accomplish this goal, but that funding must be new funding for this initiative to succeed, and will require a significant increase beyond this proposed level. We urge the subcommittee to direct specific and increased CFAR funding for this purpose.

In conclusion, the RWG calls on Congress to continue the bipartisan Federal commitment towards combating HIV as well as other chronic and life—threatening illnesses by increasing funding for NIH in fiscal year 2020. A meaningful commitment towards maintaining the U.S. pre-eminence in HIV research and fostering innovation cannot be met without prioritizing the research investment at NIH that will lead to tomorrow's lifesaving vaccines, treatments and cures that are needed to end the HIV epidemic here and abroad. Thank you for the opportunity to provide these written comments.

PREPARED STATEMENT OF RESEARCH!AMERICA

On behalf of Research!America and our alliance, which advocates for science, discovery, and innovation to achieve better health for all, thank you for this opportunity to share our views on fiscal year 2020 appropriations under the jurisdiction of the Subcommittee on Labor, Health and Human Services, Education, and Related Agencies. We are grateful that for fiscal year 2019, the committee not only bolstered the base budgets of the National Institutes of Health (NIH), the Centers for Disease Control and Prevention (CDC), and the Agency for Healthcare Research and Quality (AHRQ), but also provided dedicated funding for escalating threats such as the opioid crisis and antibiotic resistance and unique needs like the development of a universal flu vaccine.

The National Institutes of Health Drives the Discovery of New Treatments and Cures

The 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 research and innovation. According to a national survey we commissioned in January of 2019, 84 percent of Americans believe it is important for Congress and the President to assign a high priority to faster medical progress. As it stands, our Nation spends about 5 cents of each health dollar on research to prevent, cure and treat disease. Some 63 percent of Americans say that this level of investment is not enough, an 11 percentage point increase from just last year. Americans want medical progress, and they want the U.S. to do more to drive it.

More than 80 percent of NIH funding is awarded through almost 50,000 competitive grants to more than 300,000 researchers at over 2,500 universities, medical schools, and other research institutions in every State 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 while delivering substantial economic benefits. Basic research funded by the NIH fuels the entry of new drugs into the market, providing an estimated return to public investment of $1.43 for every dollar invested. The Human Genome Project has produced $1 trillion of economic growth—a 178-fold return on investment. The NIH also plays an essential role in educating and training America's future scientists and medical innovators by sponsoring training grants and fellowships for biomedical- and health-focused graduate and medical students, postdoctoral researchers and young investigators—a pivotal investment in America's future research workforce.

NIH advances the interests of America and Americans in other crucial ways. For example, the All of Us Research Program at NIH is advancing the largest clinical trial in our Nation's history to accelerate precision medicine and advance a host of other medical and health research objectives. The HEAL Initiative is conducting interdisciplinary research to end the opioid epidemic. The National Institute of Aging supports research on the health and well-being of older Americans and, through its Alzheimer's Disease Education and Referral Center, provides information on age-related cognitive changes and neurodegenerative disease. The Accelerating Medicines Partnerships unites the best of the private and public sectors, streamlining collaboration between the NIH, FDA, life science companies, and non-profit organizations working to develop treatments for Alzheimer's, Type 2 diabetes, rheumatoid arthritis, lupus, and Parkinson's disease. The National Cancer Institute's Cancer Moonshot aims to accelerate research and improve our ability to prevent and detect cancer. NIH also plays a pivotal role in the 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 funding for NIH to at least $41.6 billion in fiscal year 2020, an increase of $2.5 billion. Research!America believes this powerful infusion of funds is merited by the magnitude of our health challenges, the tangible and intangible costs of inaction, and the extraordinary return on medical progress.

The Centers for Disease Control and Prevention Safeguards the Nation's Health

CDC is tasked with protecting and advancing the Nation's health, and over the past 70 years it has worked diligently to thwart deadly outbreaks, costly pandemics and debilitating disease. Moreover, CDC plays a key role in research that leads to life-saving vaccines, bolsters our Nation's defense against and response to bioterrorism, and improves health tracking and data analytics. CDC's work has benefited America and Americans in myriad ways, including eliminating the endemic spread of rubella within the United States, playing a lead role in addressing the growing threat of antibiotic resistance, dramatically reducing the incidence of child lead poisoning, providing accurate and accessible health information, tracking and containing dangerous pandemic and epidemics, reducing deaths from motor vehicle accidents, achieving a significant expansion of newborn hearing tests and other screening measures, helping people avoid leading causes of death, and preventing millions of hospitalizations.

Ebola, Zika, dengue fever, influenza, the opioid epidemic, measles outbreaks, 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 2020, an increase of $.5 billion, to carry out its crucially important responsibilities.

AHRQ Empowers Our Nation to Spend Healthcare Dollars Wisely

AHRQ is the lead Federal agency responsible for ensuring medical progress translates into better patient care. The value of medical discovery and development hinge on smart healthcare delivery. Out of the $3.6 trillion in annual spending on healthcare, an estimated 30 percent could be prevented by addressing errors and inefficiency. AHRQ-funded research identifies and addresses this diversion of limited healthcare dollars, empowering patients to receive the right care at the right time in the right settings. For example, AHRQ-funded research has helped identify methicillin-resistant Staphylococcus aureus (MRSA) in long-term care facilities as part of an infection control strategy that limits the exposure of MRSA-free residents in order to address the rise (1 out of every 25) of hospital patients affected by healthcare-associated infections. AHRQ-funded research has played a pivotal role in reducing hospital-acquired conditions by nearly 1 million from 2014–2017, saving lives and $7.7 billion in healthcare costs.

AHRQ's evidence-based tools and resources have not only helped hospitals to reduce healthcare-associated infection rates but has been crucial in shrinking emergency room wait times from hours to minutes, improving patient safety, promoting health literacy, and reducing patient falls. From ensuring new medical discoveries reach doctors and patients as quickly as possible in rural as well as urban areas, to quantifying the scope of the opioid epidemic, 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 provide at least $460 million for AHRQ in fiscal year 2020, an increase of $122 million.

We appreciate your consideration of our funding requests and thank you for your stewardship over these critically important Federal spending priorities.

Sincerely.

[This statement was submitted by Mary Woolley, President and CEO, Research!America.]

PREPARED STATEMENT OF THE RESTLESS LEGS SYNDROME FOUNDATION

Chairman Blunt, Ranking Member Murray, and distinguished members of the Subcommittee, as you work to develop the fiscal year 2020 Labor-Health and Human Services Appropriations bill, thank you for considering the views of the community of physicians, researchers, patients, and caregivers affected by Restless Legs Syndrome (RLS). Please keep the needs of this community in mind, especially as you continue to work to address the opioid crisis.

ABOUT THE RLS FOUNDATION

The Restless Legs Syndrome Foundation is a nonprofit § 501(c)(3) organization dedicated to improving the lives of men, women, and children living with this often-devastating neurological condition. The Foundation works to increase awareness, improve treatments, and support research to find a cure. From a few volunteers meeting in a member's home in 1992, the Foundation has grown steadily; it now has members in every State, local support groups, and a track record that includes over $1.8 million provided to support fundamental research.

ABOUT RLS

Restless legs syndrome (RLS) is essentially an irregular biological drive, like hunger or thirst, that forces affected individuals to keep moving, thus reducing their ability to rest. Patients with this disease experience a deep, viscerally-irritating sensation in the legs that continues to increase until they are literally forced to move their legs or get up and walk; and this sensation only abates so long as the individual keeps moving. RLS is best characterized as a neurological, sensory-motor disorder with symptoms that are triggered from within the brain itself. It is estimated that up to 5 to 7 percent of the U.S. population may have RLS, of which half will have moderate to severe stages of the disease. RLS impacts men, women, and children, though it is 3 to 4 times more common in women and twice as common in older Americans.

Due to the inability to sleep and work, RLS can cause disability, depression, and suicidal ideation, as well as increased risk for co-morbid conditions such as heart attack, stroke, and Alzheimer's. There is no cure, and the current standards of care features several medications, which do not provide life-long coverage. One of the established effective treatment options for this disease is low-total daily dose opioid medications. These are commonly used when all other drug classes have failed. Research and clinical experience indicates that the dose of opioids typically used to manage RLS effectively without addiction or drug tolerance issues is significantly lower than dosages used to treat chronic pain.

FISCAL YEAR 2020 APPROPRIATIONS RECOMMENDATIONS

The RLS Foundation joins the broader medical research community in thanking Congress for continuing to support the National Institutes of Health with sustainable growth. Please continue to advance scientific progress through proportional funding increases by providing at least a $2.5 billion funding increase for fiscal year 2020 to bring NIH's budget up to $41.6 billion.

In this regard, please provide proportional funding increases for all NIH Institutes and Centers, including, but not limited to the National Institute of Neurological Disorders and Stroke (NINDS), the National Heart, Lung, and Blood Institute (NHLBI), the National Institute on Drug Abuse (NIDA), and the National Institute of Mental Health (NIMH). Research on RLS and similar neurological movement disorders is directly related to efforts targeting the opioid epidemic, as many patients with these disorders utilize very low total daily doses of opioid therapies to manage their condition. Additionally, related sleep disorders research activities impact many conditions and are studied across various Institutes and Centers at NIH.

RLSF joins the broader public health community in thanking Congress for providing the Centers for Disease Control and Prevention (CDC) with a modest funding increase for fiscal year 2019 and in requesting a subsequent increase of at least $500 million in discretionary resources for fiscal year 2020 to bring total agency funding up to a minimum of $7.8 billion annually.

Please also provide a dedicated, line-item appropriation of at least $250,000 to reinvigorate crucial sleep activities at CDC. Despite the success and importance of the National Healthy Sleep Awareness Project, this critical program (which had been funded for years with discretionary resources) was halted by CDC in fiscal year 2019 due to a stated lack of available funds.

RLS AND THE OPIOID CRISIS

While you consider the Committee's work to address the opioid epidemic through this fiscal year's appropriations bill, the RLS Foundation asks that you protect the needs of patient communities who depend on appropriate access to low total daily doses of opioid therapies to manage their debilitating condition. RLS is not a chronic pain condition, and many in our community utilize these medications to treat underlying neuropathology issues and not sensations of pain. Studies have shown that appropriate access to these therapies allows patients to live productive lives without an increased risk of developing opioid use disorder. As you consider various legislative proposals and work with Federal agencies, please consider the needs of patients who rely on the regular use of low total daily doses of opioids to manage RLS by supporting a diagnosis-appropriate safe harbor for RLS patients, so they do not face arbitrary barriers.

I would like to share with you the experience of Sandra Katanick from Florida, who serves on the RLS Foundation's Board of Directors:

″I have suffered with RLS for almost 15 years following a total knee replacement. I used to be on Requip, but following my augmentation, this medication only makes my symptoms worse. For 5 years, I have been fortunate to be on a very effective treatment regimen that includes a low dose of Oxycontin at bedtime. In the last year, I moved to Florida and have yet to find a physician willing to continue this treatment, despite my efforts to educate them by sharing clinical guidelines on safe and proper prescribing of opioids for RLS. I am worried that I may lose the ability to treat my disease and suffer needlessly, because State and Federal policies are being misapplied to prevent the appropriate use of opioids to treat RLS."

Sandy's story is emblematic of the need for increased medical research, access to treatment, professional education, and public awareness. Thank you for your time and consideration of our requests.

[This statement was submitted by Karla M. Dzienkowski, RN, BSN, Executive Director, Restless Legs Syndrome Foundation.]

PREPARED STATEMENT OF ROTARY INTERNATIONAL

Chairman Blunt, members of the Subcommittee:

Rotary appreciates the opportunity to encourage continuation of funding for fiscal year 2020 to support the polio eradication activities of the U.S. Centers for Disease Control and Prevention (CDC). The CDC is a spearheading partner of the Global Polio Eradication Initiative (GPEI), which is an unprecedented model of cooperation among national governments, civil society and UN agencies working together to reach the most vulnerable children through the safe, cost-effective public health intervention of polio immunization. We appeal to this Subcommittee for continued leadership to ensure we seize the opportunity to conquer polio once and for all. Rotary International requests that $176 million be provided for the polio eradication activities of the CDC—level funding—to ensure we end polio transmission, protect polio free areas, and leverage the resources developed through this global effort for value-added impact.

The United States is the leading public sector donor to the Global Polio Eradication Initiative. The 325,000 members of Rotary clubs in the US appreciate the United States' generous support and longstanding leadership. Rotary, including matching funds from the Gates Foundation, has contributed more than US $1.8 billion and thousands of hours of volunteer service to protect children from polio. Rotarians are committed to fundraising for the program until the world is certified polio free. Continued 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 support, only two countries confirmed cases of wild polio in 2018: Afghanistan and Pakistan. Wild poliovirus type 1 caused all the wild virus cases and these are found in high risk areas of Afghanistan (21 cases) and Pakistan (12 cases). Nigeria, which experienced an outbreak in 2016, has not confirmed any new cases since August of 2016 despite humanitarian crises. Continued progress to reach every child and stop polio virus transmission in these most complex environments reinforces the fact that polio eradication is feasible. While the primary focus of global efforts is on stopping transmission of endemic polio, this is followed closely by work to immunize the more than 400 million children in up to 70 countries which remain at risk for polio outbreaks. Since 2001, more than 40 countries which were polio free experienced outbreaks. While these outbreaks were stopped, they are a reminder that as long as the wild polio virus circulates anywhere, children everywhere, including the United Sates, remain at risk and must continue to be protected through immunization.

Only wild poliovirus type 1 (WPV1) is still circulating. Type 2 (WPV2) was declared eradicated in September 2015. Type 3 (WPV3) has not been seen since November 2012. Eradicating strains of the polio virus is further proof that a polio-free world is achievable.

CDC'S VITAL ROLE IN GLOBAL POLIO ERADICATION PROGRESS

The United States is the leader among donor nations in the drive to eradicate polio globally. Congressional support has enabled CDC to provide the following:

Provide Technical Leadership and Capacity Building

—Provide $ 66.6 million to WHO for surveillance, technical staff and immunization activities' operational costs, primarily in Africa; and $3 million to UNICEF to support operational costs for National Immunization Days (NIDs) in all polio-endemic and outbreak countries.

—Provide $ 28.3 million to UNICEF for the expansion of a Community Based Vaccinator Program in Pakistan that now includes over 24,000 workers (nearly 90 percent of which are women) who reach 4 million children annually with approximately 60 million doses of oral polio vaccine, and 2.9 million doses of inactivated polio vaccine.

—Train global virologists in advanced poliovirus research and public health laboratory support. CDC's Atlanta laboratories serve as a global reference center and training facility.

—Support the international assignment of 19 technical staff on direct, 2-year assignments to WHO and UNICEF to assist polio-endemic and polio-reinfected countries.

—Provide technical leadership through three international polio consultants in Pakistan and one in Afghanistan; and build capacity through eight national polio consultants in Afghanistan.

—Collaborate with the Pakistan Ministry of Health, WHO and USAID's mission in Islamabad to train and deploy 88 national epidemiologists from CDC's Field Epidemiology Training Program (FETP) to the highest risk districts for circulation of wild polio virus to improve the quality of surveillance and immunization activities there and to strengthen routine immunization systems.

—Assign 489 public health professionals who completed CDC's Stop Transmission of Polio (STOP) training program to support critical national immunization functions in 42 at-risk countries in 2018. In 2019, the STOP program has already deployed 254 professionals to 42 countries. The second STOP team is being finalized for training and deployment in June 2019.

—Train 230 staff at the Local Governing Area level in the highest risk States of Nigeria in CDC's National STOP program. These staff play a key role in interrupting transmission of wild polio. Nigeria's polio legacy planning will transition those workers to build lasting improvements in Nigeria's immunization system.

The CDC also provides the following global surveillance, virologic and other technical expertise:

—Provides expertise in virology, diagnostics, and laboratory procedures, including quality assurance, and genomic sequencing of samples obtained worldwide.

—Houses the leading specialized polio reference lab in the world which provides the largest volume of operational (poliovirus isolation) and technologically sophisticated (genetic sequencing of polio viruses) lab support to the 145 laboratories of the global polio laboratory network.

—Offers programmatic guidance and expertise for global polio eradication by participating in technical advisory groups, EPI manager and other key global meetings.

—Provides scientific and technical expertise to WHO on research issues regarding: (1) laboratory containment of wild poliovirus stocks following polio eradication, and (2) when and how to stop or modify polio vaccination worldwide following global certification of polio eradication.

—Leads the efforts to raise awareness of the importance and urgency of transition planning amongst donors, country governments and other stakeholders to begin polio legacy planning to ensure that key polio functions, including immunization, comprehensive vaccine-preventable disease surveillance, outbreak response and biocontainment, will be in place post-eradication.

In 2018, CDC also collaborated with Voice of America (VOA) to produce programs with scientifically accurate information about polio and the need for vaccinations to fight against early childhood diseases. The programs address identified vaccine issues and concerns through radio and television programming formats, including PSA's, radio dramas (if feasible), and field news reports to millions of Pashto-speaking Afghans and Pakistanis. VOA also trains journalists on "best practices" in covering polio, tracks stories written and completes data collection for monitoring and evaluation.

FISCAL YEAR 2020 BUDGET REQUEST

We respectfully $176 million in fiscal year 2020 for the polio eradication activities of CDC, the level appropriated by Congress in fiscal year 2019. With Congress' continued support for polio eradication in fiscal year 2020, CDC's priorities are to stop wild transmission in the remaining polio endemic countries and countries at-risk by strengthening surveillance, reaching all children with vaccine, and rapid case response. CDC will also work to measure and improve countries' abilities to use inactivated polio vaccine to protect their populations from polioviruses, with a particular focus on hard to reach populations at increased risk for not receiving inactivated polio vaccine. CDC will also continue to work to strengthen surveillance for polioviruses in all areas currently below certification standard. CDC has also begun planning for a post-polio transition to advance additional global vaccine-preventable diseases (VPD) control and elimination/eradication targets as outlined in CDC's Strategic Framework for Global Immunization 2016–2020.

BENEFITS OF POLIO ERADICATION

Since 1988, 18 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 $16 billion already invested in eradication. Success will ensure that the significant investment made by the US, Rotary International, and many other countries and entities, is protected in perpetuity.

[This statement was submitted by Dr. Anne L. Matthews, Chair, Rotary's Polio Eradication Advocacy Task Force.]

PREPARED STATEMENT OF THE RYAN WHITE MEDICAL PROVIDERS COALITION

Thank you for reviewing my testimony for the record. My name is Dr. Ernie-Paul Barrette, and I serve as Medical Director of the HIV Clinic for the Washington University School of Medicine, in St. Louis, Missouri, the largest providers of medical care for patients with HIV/AIDS in Missouri. I am pleased to submit testimony on behalf of the Ryan White Medical Providers Coalition (RWMPC) of the HIV Medicine Association (HIVMA), of which I am a member. HIVMA represents over 6,000 HIV clinicians and researchers. The RWMPC is a national coalition of medical providers and administrators who work in healthcare agencies supported by the Ryan White HIV/AIDS Program funded by the HIV/AIDS Bureau (HAB) at the Health Resources and Services Administration (HRSA).

I thank the Subcommittee for maintaining funding for the Ryan White Program over the previous decade of constrained budgets and limited resources. However, during the past decade, science and medicine have improved, and now expanding the Ryan White Program could help end the domestic HIV epidemic. To advance the Nation toward this goal, RWMPC and HIVMA request both $225.1 million for Part C of the Ryan White Program (a 10 percent or $24 million increase over current funding), as well as the new fiscal year 2020 funding the Administration requested for the Ending HIV as an Epidemic (EtE) initiative to expand access to HIV prevention, care, and treatment. While RWMPC and HIVMA support these EtE funding requests, it is essential that all funding for the EtE initiative be new, additional funding and not a repurposing of already stretched resources. The EtE proposal includes $291 million across several HHS agencies and programs, including $120 million for HRSA that would support $70 million for the Ryan White Program to provide additional HIV care and treatment, as well as $50 million for the Bureau of Primary Health Care to support HIV prevention services, including providing Pre-Exposure Prophylaxis (PrEP), a once-a-day medication proven to prevent HIV infection.

Washington University in Missouri is Leading the Way

Washington University's Ryan White-funded clinic has served as the leading source of HIV primary care in Missouri for over 30 years. Each year our Ryan White clinic serves more patients with more complex needs. In 2018, the HIV Clinic at Washington University experienced a 5 percent increase from 2017 in its number of patients living with HIV. Over the last thirteen years the clinic has seen a 103 percent increase in patients with HIV. Additionally, approximately 1 in 3 patients were fully uninsured and relied heavily on the Ryan White Program to fund their care, and a significant portion experienced housing insecurity.

Washington University, like most Ryan White Part C clinics, also receives support from other parts of the Ryan White Program that help us provide medications and services including additional medical care, dental services, mental health services, peer health coaches, case management, and transportation—all key components of the comprehensive Ryan White care model that produces outstanding outcomes. Additionally, Washington University provides dedicated services for women who are pregnant and for patients re-entering care after being out of care for more than 1 year. Both services include nurses and social workers that accompany patients to appointments and do home visits during these critical times.

Washington University also provides Pre-Exposure Prophylaxis (PrEP) services. This critical HIV prevention tool is integrated as part of prevention and primary care delivery. However, more support for the PrEP program is needed to scale up these services to meet patient and community needs.

Due to increased rates of hepatitis C infections, which in part are driven by the opioid epidemic, the Washington University HIV Clinic has started a hepatitis C clinic in order to treat this infection earlier. In addition, the Washington University HIV Clinic has been a leader in expanded HIV testing to identify cases, improved linkage-to-care services, and use of social media to improve engagement, retention, and medical outcomes among youth and young adult patients. However, the opioid epidemic is hitting Missouri and other parts of the U.S. hard. Washington University patients struggle not only with HIV, but also with substance use disorder and related infectious diseases, such as hepatitis C. In fact, Missouri has seen a recent dramatic increase in cases of hepatitis C.[1]

Ryan White Part C Clinics are Effective Medical Homes and Public Health Programs

Ryan White Part C directly funds approximately 350 community health centers and clinics that provide comprehensive HIV medical care nationwide, serving more than 300,000 patients each year. These clinics are the primary method for delivering HIV care to rural jurisdictions—approximately half of all Part C providers serve rural communities. Access to Ryan White Part C clinics has helped to dramatically decrease AIDS-related mortality and morbidity over the last decade. The program's comprehensive services engage and keep people in HIV care and treatment. This is critical, because HIV disease is infectious, so identifying, engaging, and retaining individuals living with HIV in effective care and treatment saves lives and benefits public health by stopping HIV transmission when individuals are virally suppressed. In 2017, 86 percent of Ryan White patients were virally suppressed—a 24 percent increase in the program-wide viral suppression rate since 2010. Washington University is in alignment with this national average—in 2018, 86 percent of Washington University patients were virally suppressed. Also, 90 percent of HIV patients remain in care at Washington University—a critical fact since HIV disease is infectious, so identifying, engaging, and retaining persons living with HIV in effective care and treatment is an essential public health outcome.

Ryan White Clinics Are on the Frontlines of the Opioid Epidemic Providing SUD Treatment

Ryan White clinics serve a significant number of individuals living with both substance use disorder (SUD) and HIV. Ryan White clinics are able to deliver a range of medical and support services needed to prevent and treat substance use disorder as well as related infectious diseases, including HIV, HCV, and sexually-transmitted infections. The significant experience and expertise of Ryan White medical providers should be fully leveraged to effectively respond to the opioid and other drug epidemic and expand access to SUD services more rapidly.

Providing non-Ryan White funding for SUD treatment and related services to Ryan White clinics would increase access to SUD treatment, overdose prevention, harm reduction, and comprehensive support services for both individuals living with HIV as well as those without HIV. Such funding would increase access to SUD treatment and related services more rapidly nationwide by using the established and effective Ryan White Program's clinic infrastructure. Leveraging this network of comprehensive care nationwide to provide medication assisted treatment, other SUD treatment, and related services more rapidly would help to improve the response to opioid and other drug epidemic and help reduce the increasing rate of opioid overdose deaths. It also would help prevent the spread of HIV and other infectious diseases while delivering SUD treatment, overdose prevention, and harm reduction services.

Ryan White Clinics Are Saving Lives and Reducing Costs

Early and reliable access to HIV care and treatment helps patients with HIV live healthy and productive lives and is more cost effective. A study from the Part C clinic at the University of Alabama at Birmingham found that patients treated at later stages of HIV disease required 2.6 times more healthcare dollars than those receiving earlier treatment meeting Federal HIV treatment guidelines.

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[1] Missouri Department of Health and Senior Services. Online at: https://health.mo.gov/data/hivstdaids/pdf/HepCKnownRisksFactSheets.pdf.

Increased Funding for Prevention at CDC and Research at NIH Also is Critical

While my testimony has focused on HRSA programs, the ability to effectively respond to the syndemics of HIV, substance use disorder, and related infectious diseases such as HCV; sexually transmitted infections; and skin, soft tissue, and endovascular infections depends heavily on CDC funding to enhance surveillance and prevention activities, and on NIH to continue to improve the tools that we have to prevent and treat HIV and SUD and to learn how to effectively implement them. We support the Administration's request for $140 million for CDC to provide surveillance, response, and other HIV prevention services as part of the EtE initiative, as well as the Administration's request for $58 million for CDC to address the infectious diseases consequences of the opioid epidemic. Finally, we support continued robust funding for NIH. This funding supports discoveries that will help to end the HIV, HCV, and opioid epidemics.

Conclusion

Thank you for your time and consideration of these requests, and please don't hesitate to contact me or Jenny Collier, Convener of the Ryan White Medical Providers Coalition, at jcollier@colliercollective.org if you have any questions or need additional information.

[This statement was submitted by Ernie-Paul Barrette, MD, Medical Director, HIV Clinic for the Washington University School of Medicine, and Member of the Ryan White Medical Providers Coalition of the HIV Medicine Association.]

PREPARED STATEMENT OF THE SAFER FOUNDATION

My name is Victor Dickson and I submit testimony on behalf of the Safer Foundation. For 47 years, Safer has provided a comprehensive continuum of workforce development and reentry services for individuals with arrest and conviction records seeking employment. There is dignity in work, and Safer Foundation believes that individuals who have made mistakes in the past should have the opportunity to be self-sufficient and contribute to their families and communities through gainful, living wage employment. Clients come to Safer because they want and need to work. Safer Foundation helps clients discover career paths that provide personal fulfillment while allowing them to earn a living. A critical Federal program that supports these efforts is the Reintegration of Ex-Offenders (RExO) program within the Employment & Training Administration of the U.S. Department of Labor. I thank the Subcommittee for providing RExO with $93 million in fiscal year 2019. Given the persistent skills gap and significant need to help employers identify qualified workers nationwide, I request $100 million for the RExO program in fiscal year 2020.

EMPLOYMENT REDUCES RECIDIVISM AND IMPROVE REENTRY OUTCOMES

Research shows that sustained, living wage employment and life skills are critical components to long-term reentry success. One study found that individuals who were employed and earning higher wages after release were less likely to return to prison within the first year.[1] Unfortunately, finding this type of employment can be prohibitively difficult for Americans who have any history of justice system involvement. The National Employment Law Project estimates that 1 in 3 American adults has a criminal record that interferes with their ability to find a job.[2] The RExO program helps individuals overcome employment barriers by preparing participants for jobs in local high-demand industries through career pathways and industry-recognized credentials.

Increasing RExO funding would expand access to comprehensive workforce development and reentry services that assist individuals with criminal records in navigating obstacles to employment while improving employment and reentry outcomes. Authorized by section 169 of Workforce Innovation and Opportunity Act (WIOA), the RExO program provides workforce preparation services for both adults and young people. RExO includes a $25 million set-aside to provide services to prepare formerly incarcerated youth for employment, including those who have not completed school or other educational programs. Research has found that incarceration reduces the average formerly incarcerated individual's earning potential by more than 27

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[1] Visher, C., Debus, S., & Yahner, J. Employment After Prison: A Longitudinal Study of Releasees in Three States. Washington, DC: Urban Institute (2008).

[2] "Research Supports Fair-Chance Policies" (March 2016), National Employment Law Project, footnote 1 on p. 7. Available at http://www.nelp.org/publication/researchsupports-fair-chance-policies.

percent over a lifetime,[3] making workforce development services for young people essential for their long-term employment and reentry success. In light of the significant costs of the criminal justice system at the state, local, and Federal levels, the RExO program is crucial to incubating community-based models of successful reentry through employment.

SAFER'S REXO SERVICES INCREASE EMPLOYMENT BY WORKING WITH EMPLOYERS AND EMPLOYEES

Safer Foundation offers a full spectrum of workforce development and reentry services that train individuals, address their reentry obstacles and needs, and help them obtain sustained employment. This holistic approach has rendered outstanding results for participants and employers. In 2006, decades of experience and success led Safer to become one of the original RExO grantees. This year, Safer expects to provide employment services to nearly 6,000 individuals with arrest and conviction records, with RExO funding providing critical support for these services.

However, in addition to working with reentering individuals and their communities, Safer also works closely with employers to identify what types of trained employees they need. The National Federation of Independent Business reports that as of 2017, 45 percent of small businesses were unable to find qualified applicants to fill job openings, including construction workers, truck drivers, industrial technicians, heavy equipment operators, computer network support specialists, and web developers. Safer can be responsive to employer needs by tailoring its programs to develop skilled workers for specific employment sectors. For example, Safer's Training to Work (T2W) program, funded by a RExO grant, has improved long-term employment prospects for clients at Safer's Adult Transition Centers (ATC). Program participants receive case management, education, and training that lead to industry-recognized credentials for in-demand employment such as forklift operation, foodservice and sanitation, welding, computer numerically control (CNC), CDL training, and Microsoft technologies. Given the program's strong employer and credentialing components, RExO is uniquely positioned to assist local organizations in developing and providing services that meet the needs of both the local business community and reentering individuals.

SAFER'S REXO GRANT PRODUCED OUTSTANDING EMPLOYMENT OUTCOMES AND REDUCED RECIDIVISM

Safer's RExO grant for the Training to Work (T2W) program significantly outperformed employment targets and dramatically reduced recidivism. For the first cohort of RExO T2W participants, 69 percent of participants obtained employment—15 percent higher than the grant's employment target. Given the success of this first cohort of participants, T2W was extended to a second cohort who did even better with an employment rate of 78 percent—30 percent higher than the grant's target. Safer's RExO T2W grant also reduced recidivism rates beyond original targets. A 2014 report published by the Bureau of Justice Statistics, which studied recidivism across 30 States for 5 years, determined that the recidivism rate 1 year after release from prison was 43.4 percent.[4] T2W's first participant cohort had an 11 percent recidivism rate, and its second participant cohort had a 9 percent recidivism rate—respectively 75 percent and 80 percent lower than the national recidivism rate.

Program evaluation has shown that such successful outcomes are related to the comprehensive service model that grantees such as Safer provide. Effective, comprehensive services can include interventions such as relationship building between staff and participants, employment verification, trauma informed training, life skills training, employment preparation, mentoring, intensive case management, strong training provider relationships and support, family involvement, and post-release follow-up and support. These comprehensive services are cost-effective—a 2016 Illinois study found that for every $1 invested in community-based employment and training programs, tax payers saw a net benefit of $20.26, and found that employ-

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[3] Holwell, P., & Gardner, D. (2014). Workforce centers: Successful labor market reentry for justice involved ex-offenders. Centennial, CO: Arapahoe/Douglas Works, p. 2: http://www.adworks.org/pdf/Supporting__Successful__LM__Reentry__for__Justice__Involved.pdf.

[4] Durose, Matthew R., Alexia D. Cooper, and Howard N. Snyder, Recidivism of Prisoners Released in 30 States in 2005: Patterns from 2005 to 2010 (pdf, 31 pages), Bureau of Justice Statistics Special Report, April 2014, NCJ 244205.

ment and training programs had the highest cost-benefit ratio for reducing recidivism.[5]

U.S. ECONOMIC SUCCESS REQUIRES INCREASED EMPLOYMENT OF INDIVIDUALS WITH CRIMINAL RECORDS

As the U.S. economy continues to rebound from the last recession, the labor market continues to tighten and the skills gap is growing. While currently the U.S. is experiencing a period of economic expansion, experts warn that this expansion will end prematurely if the U.S. does not relieve structural constraints on labor force participation, including over-expansive bans on employment of individuals with criminal records. Employment barriers faced by individuals with criminal records combined with the opioid epidemic have deflated the U.S. labor force participation rates, which are as low today as they were over 30 years ago.[6] As labor markets continue to tighten, employers are increasingly ready to give people with criminal records a fair shot, and increasingly need to do so to find and employ skilled workers. Safer has partnered with hundreds of employers to meet their workforce needs. Increased RExO funding in fiscal year 2020, including the funding of earn and learn apprenticeship opportunities for in demand skills development, would allow these efforts to expand, and could help match more employers with qualified employees who are trained, talented, and motivated to work.

CONCLUSION

By making effective workforce development and reentry services a priority, we fulfill labor market demands, contribute to a growing economy, and build strong and safe communities. Given the extensive employment and reentry needs nationwide, as well as the significant return on investment related to reduced incarceration costs and reduced crime costs borne by victims, families, and communities, I urge Congress to allocate $100 million to the RExO program in fiscal year 2020. Thank you so much for your time and consideration of this important program.

[This statement was submitted by Victor Dickson, President and CEO, Safer Foundation.]

PREPARED STATEMENT OF SAVE THE CHILDREN ACTION NETWORK

Chairwoman DeLauro, Ranking Member Cole, and honorable Members of the Subcommittee, thank you for the opportunity to provide testimony about the critical investments that must be made in early childhood education. My name is Mark Shriver and I am the CEO of Save the Children Action Network (SCAN) and Senior Vice President of U.S. Programs and Advocacy for Save the Children. SCAN is a national, non-profit organization that aims to mobilize all Americans to support critical investments in early childhood education (ECE), for children birth to age five. We advocate for robust appropriations for the Department of Health and Human Services programs of Head Start/Early Head Start, Child Care and Development Block Grants, and Preschool Development Grants, as well as the Department of Education programs, 21st Century Community Learning Centers and Promise Neighborhoods.

BACKGROUND

The changing demands of our Nation's economy, the stresses of our labor market and the challenge created by an increasing number of children being raised in single-parent families have all left low-income parents struggling with the burdens of work and parenting. By supporting critical early learning programs, not only are we investing in the lives of children, but their parents also have the ability to enter into the workforce and become productive, taxpaying members of society. This increases the economic stability of families and improves the foundation for the children's future wellbeing. Ensuring access to ECE is the most effective way to break the cycle of poverty. These investments lay the foundation for children's success later in school, career and life-and they also offer tangible returns on investment to the country as a whole, such as increased tax revenue later in life, lower justice system costs, and reduced reliance on government assistance.

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[5] Illinois Sentencing Policy Advisory Council (2016). A Cost-Benefit Tool for Illinois Criminal Justice Policymakers, pp. 2–3: http://www.icjia.state.il.us/spac/pdf/Illinois__Results__First__Consumer__Reports__072016.pdf, pp. 2–3.

[6] Bureau of Labor Statistics, U.S. Department of Labor. Available at https://data.bls.gov/timeseries/LNS11300000.

When America invests in kids, it is investing in its own economic future as well. Research shows that investments in ECE offer potential for long-term economic impact and growth. Nobel Prize-winning economist James Heckman released a report in December 2016 indicating that the annual rate of return on investments in high-quality early childhood development for children from low-income backgrounds can be up to 13 percent, per child per year, due to improved outcomes in education, health, sociability, economic productivity and reduced crime.[1]

We recognize that difficult budget decisions that need to be made. However, balancing the budget on the backs of children, who are our greatest investment and hope for the future, is not the right path forward and it is not supported by an overwhelming majority of Americans. The research is clear that doing so is against our economic interest.

SAVE THE CHILDREN'S WORK ON EARLY CHILDHOOD EDUCATION

The good news is that we know what works. Save the Children has years of experience and has long been a part of the movement to provide high-quality early childhood education in the United States. To advance early learning, Save the Children runs education programs for children at home and in the classroom. Our child experts work to ensure that our Nation's most under resourced children have the best chance for success. Every day, we help children get ready to learn, do well in school, and live healthy, active lives.

APPROPRIATIONS PRIORITIES

Child Care and Development Block Grant (CCDBG)

The most effective, efficient way to invest in child care would be through a substantial increase in funding for the Child Care and Development Block Grant (CCDBG), the major Federal child care program. The program provides vouchers directly to working families to help them afford the licensed child care provider of their choice.

The increase in child care funding in fiscal year 2018 has had tremendous benefits for children and families across the country. States have been able to make significant additional progress in implementing the reforms included in the 2014 CCDBG reauthorization law designed to ensure the health and safety of child care, improve the quality of care, and make it easier for families to obtain and retain child care assistance. For example, States have used the new CCDBG funds for purposes such as helping providers cover the costs of criminal background checks, ensuring families can receive child care assistance for a continuous 12 months to allow them to have more stable child care, supporting professional development opportunities for child care teachers, and hiring additional inspectors to monitor child care programs.

Despite this progress, further investments are needed to fully compensate for years of stagnant funding. Total funding for child care (including CCDBG funds and Temporary Assistance for Needy Families funds used for child care) in fiscal year 2018 remained nearly $1 billion short of the total funding level in fiscal year 2001 after adjusting for inflation. As a result, many families are still unable to access help paying for care due to State income limits that remain low or waiting lists that remain long, and many child care providers-particularly those in low-income neighborhoods-still struggle to stay in business due to payment rates that remain low. For these reasons, we support a $5 billion increase to CCDBG.

Head Start and Early Head Start

Head Start and Early Head Start are key to providing and expanding comprehensive early care and education to our poorest children. Head Start programs promote the school readiness of young children from low-income families by supporting their comprehensive development. Head Start also requires strong parent engagement. This dual generation support for families increases the positive benefits of the program. Adequate investment in Head Start is critical to ensure that more eligible children develop the skills that will foster their success once they transition to elementary school and beyond.

Head Start has served over 33 million children and families in communities across the country since 1965, and continues to serve nearly a million children every year. However, at the current level of funding, Head Start serves less than half of eligible preschoolers. Moreover, some of the Head Start programs can only offer partial day and/or partial year programming. These shortfalls in service delivery ham-

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[1] Jorge Luis Garcia, James J. Heckman, Duncan Ermini Leaf, and Maria Jose Prados, "The Life-Cycle Benefits of an Influential Early Childhood Program," The Heckman Equation, (2016), https://heckmanequation.org/resource/lifecycle-benefits-influential-early-childhood-program/.

per the development and interrupt stable care of children and add an extra burden on parents/caregivers to identify alternative care options, which may be costly or lower quality. Proposals for more Head Start programs to provide full-day, full-year services would ensure our lowest-income children receive a strong early learning experience. This change, however, will require additional investments so that the increased hours and days of programming do not result in cuts in the number of children participating in Head Start, the number of staff employed by programs, or impact the quality of programming provided.

Additionally, while the very early years of a child's life are critical to their development, Early Head Start serves less than 5 percent of eligible infants and toddlers. Increased funding is required to expand access to this life-changing program.

We also support the Early Head Start-Child Care Partnerships, which have shown promising results in States and communities by assisting in the expansion of high-quality early learning opportunities for infants and toddlers. These partnerships aim to better align early childhood policies, regulations, resources, and quality improvement support at national, State, and local levels. They also aim to obtain greater community buy and support of about higher-quality child care requirements. These partnerships build the capacity of the community and providers, while also incorporating Early Head Start's high standards.

Building on increases in fiscal year 2019, we encourage you to direct funding increases for Head Start and Early Head Start into three areas. First, we ask that you provide $250 million to support the Head Start and Early Head Start workforce through a cost of living adjustment in line with inflation. Second, we recommend an increase of $745 million for quality improvement funding specifically focused on addressing the impacts of trauma and Adverse Childhood Experiences (ACES) on children in Head Start and Early Head Start. Quality improvement funding allows for each grantee to tailor supports for the unique needs of children and families in their community. Finally, we ask that you continue building on recent increases in Early Head Start with $500 million in additional funding to expand critical high-quality services for infants and toddlers.

Preschool Development Grants (PDG)

The Preschool Development Grant program provides States funding to establish or expand their own pre-kindergarten programs to serve more children and increase the quality of these programs. With continued funding, States will be able to expand their preschool programs and provide this important opportunity to more children. In its first 4 years, this program reached over 170,000 children who otherwise would not have had access to preschool. States' commitment to increasing access to high-quality preschool opportunities is extremely high, as is their eagerness to partner with the Federal Government in this endeavor.

Expanded investments in Preschool Development Grants will enable more children to take advantage of early learning opportunities that encourage their learning and growth and will support efforts to further strengthen the quality of these programs. Research has demonstrated that high-quality early education has long-term benefits for children, especially low-income children, which far exceed the costs. Children who participate in high-quality early education programs have a reduced need for special education, improved health outcomes, higher rates of high school and college graduation, decreased dependence on welfare programs, and increased workforce productivity. We therefore request $400 million in funding for this program.

21st Century Community Learning Centers (CCLC)

The CCLC program supports the creation of community learning centers that provide academic enrichment opportunities during non-school hours for children, particularly students who attend high-poverty and low-performing schools. The program helps students meet State and local student standards in core academic subjects, such as reading and math, and offers students a broad array of enrichment activities that can complement their regular academic programs. Additionally, the program offers literacy and other educational services to the families of participating children. Under ESSA, funds can also be used to pay for additional time, support and enrichment activities during the school day.

Every day 11.3 million children are alone after school and are unsupervised for an average of seven hours per week. Parents of more than 19.4 million youth say their children would participate in an afterschool program if one were available in their community. Programs like CCLC help working families, keep young people safe during the hours after school when juvenile crime peaks, and improve academic achievement. These programs also provide children with physical activity and engage them in their learning. Without funding for afterschool and summer learning programs, students will lose out on essential learning opportunities that help them prepare for school, college and careers. We urge Congress to support this important program with funding of $1.32 billion so that services may continue and the academic and developmental outcomes of children can be improved.

Promise Neighborhoods

The Promise Neighborhoods program is authorized under the Elementary and Secondary Education Act of 1965, as amended by ESSA.[2] The program supports the implementation of innovative strategies that improve outcomes for children in the Nation's most distressed communities. To do so, communities must build a continuum of supports for children, from cradle to career. This program increases the capacity of community leaders and organizations to plan, implement and track progress toward specified outcomes. These outcomes include students entering kindergarten ready to succeed in school, graduating from high school and feeling safe at school and in the community. The program also tracks 15 indicators to measure success, including attendance, graduation and student mobility rates, and participation in daily physical activity. This holistic approach to improving the educational achievement of low-income students ensures sustainable, community-driven changes and interventions.[3]

Since its creation in 2010, this innovative program has continued to fund communities with demonstrated success as well as award funding to new communities who create thoughtful plans for change. This program is a strategic investment in high-needs communities, so we ask Congress to make the smart investment of $78.25 million for Promise Neighborhoods.

CONCLUSION

On behalf of Save the Children Action Network, and our advocates across the country, I want to thank the Subcommittee for its continued leadership on early childhood education programs and its demonstrated bipartisan support for these priority programs in the fiscal year 2019 appropriations process. I ask that you now continue to make a robust investment in early childhood education in fiscal year 2020. We appreciate the Subcommittee's support for programs that are essential to giving children opportunity for success. We ask for your continued partnership in investing in children, increasing access to opportunity, and ensuring a more prosperous America for generations to come.

[This statement was submitted by Mark Shriver, CEO, Save the Children Action Network.]

PREPARED STATEMENT OF THE SCLERODERMA FOUNDATION

THE FOUNDATION'S FISCAL YEAR 2020 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.
  - —A proportional fiscal year 2019 funding increase for CDC's National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP).
- —At least $41.6 billion in program funding for the National Institutes of Health (NIH).
  - —Proportional funding increases for NIH's National Heart, Lung, and Blood Institute (NHLBI); National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS); National Center for Advancing Translational Sciences (NCATS).

Chairman Blunt, Ranking Member Murray and distinguished members of the Subcommittee, thank you for your time and your consideration of the scleroderma community's priorities while working to craft the fiscal year 2020 L–HHS Appropriations Bill.

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[2] https://innovation.ed.gov/what-we-do/parental-options/promise-neighborhoods-pn/.

[3] https://www.brookings.edu/research/the-harlem-childrens-zone-promise-neighborhoods-and-the-broader-bolder-approach-to-education/.

ABOUT SCLERODERMA

Scleroderma, or systemic sclerosis, is a chronic connective tissue disease generally classified as one of the autoimmune rheumatic diseases. The word "scleroderma" comes from two Greek words: "sclero" meaning hard, and "derma" meaning skin. Hardening of the skin is one of the most visible manifestations of the disease. The disease is also known as "systemic sclerosis," a subset of the disease in which internal organ systems (such as kidneys, lungs, heart, and gastrointestinal track) and skin, or internal organ systems only, are affected. It is estimated that about 300,000 Americans have scleroderma with one-third of those having the systemic form of the disease. Scleroderma varies from patient to patient and often presents with symptoms similar to other autoimmune diseases, making diagnosis and treatment extremely complicated. There may be many misdiagnosed or undiagnosed cases. Currently, there is no cure for scleroderma.

ABOUT THE FOUNDATION

The Scleroderma Foundation is dedicated to the concerns of people whose lives have been impacted by the autoimmune disease scleroderma, also known as systemic sclerosis, and related conditions. The Foundation's mission is to 1) support affected individuals, 2) promote education and public awareness, and 3) advance critical research and improve scientific understanding to improve treatment options and find cures. The Foundation has a research program that funds clinical research to find the cause and cure for scleroderma and related conditions.

CENTERS FOR DISEASE CONTROL AND PREVENTION

Early recognition and an accurate diagnosis of scleroderma can improve health outcomes and save lives. CDC in general and the NCCDPHP specifically have programs to improve public awareness of scleroderma and other rare, life-threatening conditions. Please increase funding for CDC and NCCDPHP so that the agency can invest in additional, critical education and awareness activities that have the potential to improve health and save lives.

NATIONAL INSTITUTES OF HEALTH

NIH continues to work with the Foundation to lead the effort to enhance our scientific understanding of the mechanisms of scleroderma with the shared goal of improving diagnosis and treatment, and ultimately finding a cure. Since scleroderma is a systemic fibrotic disease it is inexorably linked to other manifestations of fibrosis such as cirrhosis, pulmonary fibrosis, and the fibrotic damage resulting from heart attack. Scleroderma is a prototypical manifestation of fibrosis as it impacts multiple organ systems. In this way, it is important to promote cross-cutting research across such Institutes as NIAMS and NHLBI.

Please provide NIH with a significant funding increase to the scleroderma research portfolio can continue to expand and facilitate key breakthroughs.

- —NIH continues to support the Trans-NIH Working Group on Fibrosis which is working to promote cross-cutting research across Institutes.
- —NHLBI, which is leading Scleroderma Lung Study II, is comparing the effectiveness of two drugs in treating pulmonary fibrosis in scleroderma.
- —NIAMS is leading efforts to discover whether three gene expression signatures in skin can serve as accurate biomarkers predicting scleroderma, and investigations into progression and response to treatment to clarify the complex interactions of T cells and interleukin-31 (IL–31) in producing inflammation and fibrosis or scarring in scleroderma.

Patient Perspective

My constantly aching hands begged for mercy of just one day without pain. My joints started to feel like they were being torn away from my body. Anytime I touched something cold, my hands would tingle and burn. Painful sores started appearing on my knuckles. You stole my skin color and with that went my confidence. It was like I was turning into a mummy as my skin tightened with collagen, day by day. I was beginning to need help performing small tasks. Opening a water bottle or turning a key in the door started to become difficult. Standing for long periods of time made my hips radiate with pain. In 2012 I had to stop working, at 24 years old. The definition of normal as I knew it was being torn down and built into something completely new. And so was my soul.

I now need help with everything! Getting dressed, washing my hair, cleaning, doing laundry; pretty much anything I have to use my hands for. You stole my independence. I had to learn to swallow my pride and ask for help. It's a tough thing to do, especially when you're at an age that's supposed to be your prime. Friends and family around me have blossomed into caregivers and helping me has become second nature to them. It's a beautiful thing when those surrounding you automatically adapt to your disability. Support is the lifeboat that keeps me afloat."

—*Excerpt from "My Letter to Scleroderma"*
Jessica Messingale
Coconut Creek, Florida

[This statement was submitted by Mr. Robert J. Riggs, Chief Executive Officer, Scleroderma Foundation.]

PREPARED STATEMENT OF SHANNON TOOLIS AND ROBERT KLOECKER

OVERVIEW

We are the Illinois parents of a 6 year old son who was diagnosed in 2018 with Celiac Disease, a serious autoimmune disease that afflicts about 3 million Americans. We echo the recent testimony of Marilyn Geller, CEO of the Celiac Disease Foundation, to the U.S. House of Representatives Committee on Appropriations, Subcommittee on Labor, Health and Human Services, Education, and Related Agencies, when Geller stated, "If I leave you with one message today, it is that Celiac Disease is, in fact, a serious autoimmune disease that is not being taken seriously enough by our government."[1]

Today, many people have conflated the popular Gluten Free diet craze with the medically required Gluten Free diet for people with Celiac Disease. In 1952, it was first discovered that Gluten was the trigger of Celiac Disease.[2] To cure Celiac Disease, we need to fundamentally shift how our government leaders are educated on this disease. Why? Because the current research paradigm for Celiac Disease, one that has existed for many decades, has not delivered a cure or even a way to treat accidental ingestion of Gluten. There is no medicine or surgery available to treat Celiac Disease. To date, Celiac Disease research has produced only a single approved treatment—strict adherence to a lifelong Gluten Free diet with no exceptions! However, as Celiac Disease researchers have found, "[t]here is no such thing as a gluten-free diet because of the constant risk of cross-contact with gluten, and gluten is in 80 percent of our foodstuffs."[3] Additionally, for up to 30 percent of patients, diet alone is inadequate for remission in that it alleviates some symptoms, but does not heal and resolve intestinal damage caused by Celiac Disease.[4]

Anecdotally, we can attest to the treatment burden, including the need to research every item that our son eats, the requirement to stay ahead of any food being served at school or activities and to provide gluten-free alternatives, and the constant concern over cross contamination whenever eating outside of home. Research has shown that the treatment burden of Celiac Disease is comparable to end-stage renal disease, and the partner (or parent) burden is comparable to caring for a patient with cancer.[5]

While the NIH purportedly makes decisions on what diseases deserve Federal research funding based on disease burden and prevalence, NIH has seriously underfunded Celiac Disease over the last decade, even as the number of Americans diagnosed with Celiac Disease has kept increasing. Moreover, as detailed herein, NIH funding for Celiac Disease has significantly trailed comparable diseases that have the same or less prevalence, the same or less disease burden measurements, as well as more than one available treatment option. We need the U.S. government, including the NIH and CDC, to start to invest meaningful resources to find a cure to this debilitating disease that directly impacts the lives of 1 percent of Americans, in ad-

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[1] Testimony of Marilyn G. Geller, CEO, Celiac Disease Foundation (Los Angeles, CA), to the U.S. House of Representatives Committee on Appropriations, Subcommittee on Labor, Health and Human Services, Education, and Related Agencies, April 9, 2019, https://celiac.org/april-2019-congressional-testimony-by-ceo-marilyn-g-geller/?

[2] "From Mussels to Bananas to Gluten: Celebrating Samuel Gee & Advances in celiac Disease Research," Beyond Celiac, August 27, 2018, https://www.beyondceliac.org/celiac-disease-news/celebrating-celiac-awareness-day-2018/

[3] Testimony of Marilyn G. Geller, April 9, 2019.

[4] Celiac Disease Foundation, https://celiac.org/about-celiac-disease/poorly-responsive-celiac-disease/.

[5] "Patient Perception of Treatment Burden is High in Celiac Disease Compared to Other Common Conditions," PMC, National Library of Medicine, National Institutes of Health, July 1, 2014, https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4159418/, and "What is Celiac Disease?", Celiac Disease Foundation, https://celiac.org/about-celiac-disease/what-is-celiac-disease/.

dition to their families and/or partners, on a daily basis. Celiac Disease is so serious that it is a "disqualifying condition" from service in the U.S. Military.[6]

SUGGESTED REPORT LANGUAGE TO THE NIH

We are respectfully asking that the Senate Appropriations Committee include the following Report Language to the National Institutes of Health:

> "The Committee recognizes the serious issue of Celiac Disease which affects more than 3 million Americans, and that the number afflicted is growing. To that end, the Committee urges NIH to devote sufficient, focused research to the study of Celiac Disease. To date, NIH has examined symptoms of Celiac Disease and has not focused upon the autoimmune causation underpinning the affliction. Today, the only known treatment for this disease is a Gluten Free diet; but, recent private sector research has revealed that such a treatment is insufficient for many who suffer from Celiac Disease. Therefore, the Committee directs the Office of the Director to dedicate sufficient resources and robust investment toward multi-institute research to better coordinate existing research and focus new research efforts toward understanding causation and ultimately, finding a cure. The Office of the Director is directed to submit its plan for coordination and execution of this research to the Senate Appropriations Committee, including the funding and FTE associated with implementation of this plan, no later than 60 days after the date of enactment of this Act."

What is Celiac Disease?

Answer. An Invisible Illness with a Major Impact on People's Health

According to the University of Chicago Celiac Disease Center, "Celiac disease is an inherited autoimmune disorder that affects the digestive process of the small intestine. When a person who has celiac disease consumes gluten, a protein found in wheat, rye and barley [gluten helps food items maintain their shape, acting as a glue that holds food together[7]], the individual's immune system responds by attacking the small intestine and inhibiting the absorption of important nutrients into the body."[8] "Specifically, the tiny fingerlike protrusions called villi on the lining of the small intestine are lost [damaged]."[9] 30–40 percent of Americans carry the genes for Celiac Disease, but only about 1 percent have Celiac Disease. No one knows what causes Celiac Disease to activate in some people, but not others. This is one of the key research areas that needs funding. Additionally, Celiac research has the potential to enhance understanding and improve therapies for other auto-immune conditions and unlock the mysteries of the microbiome which may enable treatment for a wide spectrum of diseases.

Our Son's Potential Reactions to Ingestion of Gluten

For all Celiac Disease sufferers such as our son, the Gluten protein (even in trace amounts such a crumb) can pose a severe health risk for:

—Short-term sickness including abdominal pain, gas, diarrhea and/or vomiting; and

—Long-term damage to the small intestine (which affects his ability to absorb nutrients required for proper growth and development), and an increased risk of other medical conditions including, but not limited to, auto-immune thyroiditis, liver disease, inflammatory bowel disease, osteopenia, osteoporosis, infertility, neurological conditions, cancer (lymphoma),[10] and immunological scarring.[11]

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[6] U.S. Department of Defense, "DoD Instruction 6130.03, Medical Standards for Appointment, Enlistment, or Induction into the Military Services," Section 5.12.c.(3), May 6, 2018, https://www.esd.whs.mil/DD/.

[7] "What is Gluten?", Celiac Disease Foundation, https://celiac.org/gluten-free-living/what-is-guten/.

[8] University of Chicago Celiac Disease Center, Facts and Figures, https://www.cureceliacdisease.org/wp-content/uploads/341__CDCFactSheets8__FactsFigures.pdf.

[9] University of Chicago Celiac Disease Center, https://www.cureceliacdisease.org/overview/.

[10] Beyond Celiac, Fast Facts about Celiac Disease Infographic, www.beyondceliac.org , and https://www.beyondceliac.org/60forceliac/Fast-Facts-about-Celiac-Disease-Infographic/1448/.

[11] Celiac Disease Foundation, "Chronic Inflammation Permanently Alters Immune Cells in Celiac Patients," https://celiac.org/about-the-foundation/featured-news/2019/02/chronic-inflammation-permanently-alters-immune-cells-in-celiac-patients/.

Food Allergies Significantly Impact Psychosocial Well-Being[12] *of Children with Food Allergies*

For all intents and purposes, Gluten is poison to our son's body, and it is analogous to the serious danger that peanuts pose to those who are afflicted with nut allergies. Eating Gluten does not initiate an anaphylactic cascade reaction in Celiac Disease patients. However, the ingestion of Gluten, even accidental ingestion of a trace amount of Gluten, can sicken and endanger (set back) the healing of a patient's small intestine enabled through his/her strict adherence to a Gluten Free diet, and/or trigger new damage to the small intestine that could take additional years to heal. There is no medicine available (i.e., epinephrine pen for nut allergies) to take to treat any accidental ingestion of Gluten.

According to the CDC, "Many studies have shown that food allergies have a significant effect on the psychosocial well-being of children with food allergies and their families."[13] According to the University of Chicago, "Living healthily with Celiac Disease requires skill in negotiating the everyday environment—especially for children and teens, where most positive social encounters, from school lunches to prom,ares organized around food."[14]

Disparities Among Gastrointestinal Disorders in Research Funding From NIH

To understand and correct the historically inadequate NIH funding of Celiac Disease, it is instructive to read the peer reviewed academic analysis published in 2017 by the American Gastroenterological Association entitled, "Disparities Among Gastrointestinal Disorders in Research Funding From the National Institutes of Health," that was written by some of the world's leading GI researchers, which found that, out of various Gastrointestinal Disorders:

> "Celiac disease consistently received the lowest amount of NIH funding over the 5-year period, at approximately $3 million per year."
>
> "Celiac disease consistently received the lowest amount of NIH grants, at approximately eight grants per year."
>
> "Barrett's esophagus, with a prevalence of approximately 1 percent, received $64.1 million over the 5-year period. Celiac disease, with prevalence very similar to that of Barrett's Esophagus at approximately 1 percent, received significantly less funding over the 5-year period at $15.4 million—the lowest amount of all the diseases studied."
>
> "Although there is no global metric for disease importance, it is difficult to justify on medical and scientific bases a reason for such large and persistent funding differences. Although Crohn's disease has many available and emerging treatment options, celiac disease, for example, is more prevalent and has no current treatment available to patients beyond the burdensome gluten-free diet; however, celiac disease received only a small fraction of the funding that Crohn's disease received from the NIH over the 5-year period."
>
> "In conclusion, NIH funding of GI diseases is not proportional to disease prevalence or mortality. These data further suggest that a few diseases, including IBS and celiac disease, are underfunded in comparison with other diseases, especially when the prevalence, burden, and available treatment options are considered. Plausible reasons for this disparity include varying numbers of established research programs to recruit young investigators, fewer grants submitted because of a lack of investigators in the field owing to poor funding, and narrow expertise of peer reviewers on NIH review committees. In contrast with disorders with low funding levels, ample public and private funding of Crohn's disease allows for excellent research, which in turn, favors more awards of research funding. This may seem circuitous; however, funding of Crohn's disease research provides an example of the way in which success breeds success."[15] (emphasis added)

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[12] Beyond Celiac, Psychosocial Impacts of Celiac Disease Infographic, https://www.beyondceliac.org/60forceliac/Psychosocial-Impacts-of-Celiac-Disease-Infographic/1450/.

[13] U.S. Department of Health and Human Services, Centers for Disease Control and Prevention, "Voluntary Guidelines for Managing Food Allergies in schools and Early Care and Education Programs" (footnotes 39–45), https://www.cdc.gov/healthyschools/foodallergies/pdf/13_243135_A_Food_Allergy_Web_508.pdf.

[14] University of Chicago Celiac Disease Center, 2018 Year End Report, https://www.cureceliacdisease.org/wp-content/uploads/CdC_YearEnd_Report_18_WEB.pdf.

[15] "Disparities Among Gastrointestinal Disorders in Research Funding From the National Institutes of Health," The American Gastroenterological Association, By: Emma Clerx, Harvard University; Sonia Kupfer, Celiac Disease Center at University of Chicago; and Daniel Leffler,

Continued

For fiscal year 2020, we are respectfully requesting that NIH model its funding of Celiac Disease research on its funding model and scale for research on Crohn's Disease. In spite of a lower number of disease specific mortalities as well as many available and emerging treatment options, Crohn's disease received about 40 NIH grants per year averaging about $16 million annually from 2011–2015, in comparison to Celiac Disease which received about 8 NIH grants per year averaging about $3.0 million annually from 2011–2015. In 2018, the NIH RePORT suggests that Celiac Disease research received a modest increase to 13 grants totaling approximately $4.7 million. In contrast, in 2018, NIH research funding for Crohn's disease encompassed 210 grants totaling $69 million.

Notwithstanding the Herculean efforts by some brilliant, small and under-resourced research teams and advocacy groups, the paucity of NIH funding has created a vacuum and stifled innovation in the efforts to treat and cure Celiac Disease. This can change in fiscal year 2020 with meaningful NIH funding that validates research ready initiatives at multi-institute translational research centers including at the University of Chicago Celiac Disease Center, Celiac Disease Center at Columbia University, the Harvard Medical School Celiac Research Program and the Children's Hospital of Philadelphia Center for Celiac Disease.

PREPARED STATEMENT OF THE SLEEP RESEARCH SOCIETY AND PROJECT SLEEP

FISCAL YEAR 2020 APPROPRIATIONS RECOMMENDATIONS

- —SRS joins the broader medical research community in thanking Congress for providing a $2 billion funding increase for the National Institute of Health (NIH) for fiscal year 2019 and in requesting a subsequent increase of at least $2.5 billion for fiscal year 2020 to bring total agency funding up to a minimum of $41.6 billion annually.
  - —Please provide proportional funding increases for all NIH Institutes and Centers, including in particular the National Heart, Lung, and Blood Institute (NHLBI), which houses the National Center on Sleep Disorders Research (NCSDR). Sleep impacts nearly every body system and the progress of many illnesses. As a result, nearly every NIH Institute and Center conducts sleep research, and NCSDR helps coordinate sleep research activities across (and not just across NIH, but across the Federal Government, including the Department of Defense and the Veterans Administration).
- —SRS joins the broader public health community in thanking Congress for providing the Centers for Disease Control and Prevention (CDC) with a modest funding increase for fiscal year 2019 and in requesting a subsequent increase of at least $500 million in discretionary resources for fiscal year 2020 to bring total agency funding up to a minimum of $7.8 billion annually.
  - —Please also provide a dedicated, line-item appropriation of at least $250,000 to reinvigorate crucial sleep activities at CDC. Despite the success and importance of the National Healthy Sleep Awareness Project, this critical program (which had been funded for years with discretionary resources) was halted by CDC in fiscal year 2019 due to a stated lack of available funds.

Chairman Blunt, Ranking Member Murray, and distinguished members of the Subcommittee, thank you for considering the views of the sleep, circadian, and sleep disorders advocacy community as you work on fiscal year 2020 appropriations for relevant medical research and public health programs. We would like to take this opportunity to thank you for providing meaningful investment in fiscal year 2019 for NIH and CDC and to request that this investment continue in fiscal year 2020 considering recent progress and emerging opportunities.

ABOUT THE SLEEP RESEARCH SOCIETY

The Sleep Research Society (SRS) was established in 1961 by a group of scientists who shared a common goal to foster scientific investigations on all aspects of sleep, circadian rhythmicity, and sleep disorders. Since that time, SRS has grown into a professional society comprising over 1,300 researchers nationwide. From promising trainees to accomplished senior level investigators, sleep and circadian research has expanded into areas such as psychology, neuroanatomy, pharmacology, cardiology,

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North American Society for the Study of Celiac Disease, Beth Israel Deaconess Medical Center; September 4, 2017, https://www.gastrojournal.org/article/S0016-5085(17)36084-5/pdf.

immunology, metabolism, genomics, and healthy living. SRS recognizes the importance of educating the public about the connection between sleep, circadian rhythmicity, and health outcomes. SRS promotes training and education in sleep and circadian research, public awareness, and evidence-based policy, in addition to hosting forums for the exchange of scientific knowledge pertaining to sleep and circadian rhythms.

ABOUT PROJECT SLEEP

Project Sleep is a 501(c)(3) non-profit organization raising awareness about sleep health and sleep disorders by working with affected individuals and families across the country. Believing in the value of sleep, Project Sleep aims to improve public health by educating individuals and policymakers about the importance of sleep health and sleep disorders. Project Sleep will educate and empower individuals using events, campaigns, and programs to bring people together and talk about sleep as a pillar of health.

CDC SLEEP DISORDERS ACTIVITIES

For nearly a decade, CDC has supported the National Healthy Sleep Awareness Project (NHSAP) with discretionary resources at about $250,000 annually. Despite the severity and prevalence of sleep-related health issues, NHSAP represented the only public health activity at CDC devoted to sleep. This project has been highly successful by leveraging voluntary contributions from leading sleep centers and organizations to generate numerous research advancements, awareness campaigns, professional publications, and peer-reviewed articles.

Despite the overwhelming support for the NHSAP and the request to continue its core functions through key committee recommendations, CDC terminated these activities for fiscal year 2019 (effectively halting sleep-related public health efforts). These sleep efforts should be reinvigorated for fiscal year 2020 with a dedicated appropriation at the previous level of $250,000 annually. Healthy sleep is a public health challenge on par with other contemporary areas of focus, such as smoking cessation and obesity. This timely modest investment will ensure the continuation of recent efforts and continue to pay dividends in terms of patient outcomes and public health benefits.

NIH SLEEP DISORDERS ACTIVITIES

Over recent years, NIH has seen a meaningful infusion of essential funding. This investment has improved grant funding pay lines, led to significant scientific advancements, and helped to prepare the next generation of young investigators. Due to the high quality of the science, the sleep research portfolio has done well as a result of this additional funding. In fact, NIH supported research was critical to the circadian research project that received the 2017 Nobel Prize in Physiology and Medicine. However, while the sleep portfolio overall is strong, one area of potential improvement is investment in individual sleep disorders. The research portfolios for specific conditions at NIH, including Restless Legs Syndrome, circadian rhythm disorders, and Narcolepsy, remain relatively modest. The research done in these portfolios has a direct and sometimes immediate impact on patient health and wellness.

Recently, the committee reports accompanying the L–HHS appropriations bills have featured timely recommendations that emphasize the value and importance of sleep, sleep disorders, and circadian research. Moving forward, please continue to recognize the progress made by NCSDR and the need to continue to advance this research portfolio in a way that capitalizes on emerging opportunities for patient benefit.

COMMUNITY STORY: MATTHEW—TENNESSEE

Matthew Horsnell, age 37, is a life-long resident of Nashville, TN, and the proud father of two daughters, ages 14 and 12, and a son, age 6. Matthew was diagnosed with narcolepsy with cataplexy at age 25 after 12 years of battling excessive daytime sleepiness and involuntary muscle paralysis triggered by emotions (cataplexy). Daily and nightly medications improve his quality of life but do not erase his symptoms. In addition, he was diagnosed with obstructive sleep apnea at age 30, requiring the use of a CPAP device nightly. The combination of these conditions has a profound impact on Matthew's life and his ability to support his family as a single father. Currently, Matthew works part-time while also finishing up his liberal studies degree at Belmont University. Despite the adversity he faces daily, one of Matthew's hobbies is strength training and he considers himself "the World's Strongest

Person living with narcolepsy with cataplexy." Advancements in research are critical to improve the lives of people like Matthew and their families.

[This statement was submitted by Andrew Krystal, MD, MS, President, Sleep Research Society, and Julie Flygare, Founder, Project Sleep.]

PREPARED STATEMENT OF SMART RECOVERY

It is an honor to present testimony to the Subcommittee.

SMART Recovery believes that, with regard to the fiscal year 2020 appropriations for the Substance Abuse and Mental Health Services Administration, of the U.S. Department of Health and Human Services:

—0.8 percent of such sums appropriated for the Substance Abuse Prevention and Treatment Block Grant program shall be made directly available to develop the capacity and infrastructure of evidence-based mutual aid recovery support programs of national organizations which expressly support Medication-Assisted Treatment; and

—Grants made pursuant to the Substance Abuse Prevention and Treatment Block Grant program shall be for purposes which include developing and sustaining meetings of evidence-based mutual aid recovery support programs which expressly support Medication-Assisted Treatment.

We believe that for several reasons.

SMART Recovery is a 25-year-old non-profit (and virtually all volunteer) evidence-based support program for individuals with substance use disorders, including opioid use disorders. SMART stands for Self-Management and Recovery Training, reflecting its focus on self-empowered mutual support.

The addiction crisis and particularly the opioid epidemic—even with billions of dollars in appropriations and significant new authorizing legislation—is years away from being under control. Drug overdoses alone in 2017 took 70,000 lives—two-thirds of them from opioids. The 47,000 opioid overdoses that year are well past the peak of the AIDS epidemic (nearly 42,000 deaths in 1996).

The many causes of the addiction crisis (including the opioid crisis) have created for the foreseeable future a grisly new normal in the many people in need of help, including the millions of Americans suffering from substance use disorders and the family members and friends trying to care for them.

For inclusion in the hearing record, I am providing a document titled "SMART Recovery Fast Facts," which summarizes our understanding of the severity of the problem and how the SMART Recovery meetings, tools, and program dramatically help people in need. Our tools and principles are based on the proven cognitive and motivational therapies most widely used in addiction treatment.

Dr. Elinore McCance-Katz, Assistant Secretary of the Department of Health and Human Services for Mental Health and Substance Use, has stated on several occasions that "Medication-Assisted Treatment combined with psychosocial therapies and community-based recovery support is the gold standard for treating opioid addiction."

SMART Recovery is the largest community-based recovery support program that expressly and affirmatively supports Medication-Assisted Treatment and mental healthcare. Better known support programs have not expressed support, and people undergoing such treatment cannot find the help they need at many meetings.

If the funds appropriated by Congress and provided via grants to the States are to be effective, the funds spent on prevention and formal treatment must be coupled with recovery support that endorses those other two key components of what Assistant Secretary McCance-Katz regards as the treatment gold standard, a view widely shared by experts in the addiction field.

As it stands now, SMART Recovery holds well over 3,000 meetings worldwide, and about 1,850 meetings within the United States. In order to address the clear public need in this country, doubling or even tripling the number of meetings provided by SMART Recovery will be required.

Based on our accelerating growth rate in recent years, we believe we are capable of such further growth PROVIDED we had a modest level of additional outside resources to improve our office and technological infrastructure and to provide start-up assistance for the new meetings. Our meetings are free to attend but require trained facilitators (at a cost of $100 per person), rented rooms, handbooks for attendees, whiteboards, flip charts, office supplies and administrative support from SMART Recovery's central office in Ohio.

To serve rural areas and people who cannot attend meetings in person, we are increasing our number of online meetings that enable interaction through video links. We currently offer 36 online meetings and we need to increase that number to at least 100.

It is not uncommon (and we can supply examples of other programs, including HHS programs) for a very small portion of funds under a block grant program to be set aside and provided directly on a contract basis to entities in need of technical and infrastructure assistance that, once assisted, will help fulfill the purposes of the overall program.

Our other request—that grant recipients use some portion of its funds for recovery programs that are evidence-based and expressly endorse Medication-Assisted Treatment—would make the use of other funds received via grants much more effective.

The State of Connecticut, though the Connecticut Recovery Oriented Support System for Youth (or CROSS) initiative, has already used a small portion of funds received from SAMHSA to help develop SMART meetings statewide for the simple reason that peer support of the type that SMART Recovery offers makes the other funds provided by Congress to address the opioid crisis more effective.

As a final point, our requests do not require any level of appropriations beyond what would otherwise be provided by Congress.

All we request is that a small portion of fiscal year 2020 funds be used in the most cost-effective way possible to help expand the number of evidence-based recovery support meetings that—when combined with the proper medication and mental healthcare—will help alleviate the addiction crisis, and especially the opioid epidemic.

I will be happy to provide any additional information and to answer any questions.

Thank you.

[This statement was submitted by Bill Greer, President, SMART Recovery.]

PREPARED STATEMENT OF THE SOCIETY FOR MATERNAL-FETAL MEDICINE

On behalf of the Society for Maternal-Fetal Medicine (SMFM), I am pleased to submit testimony in support of the important work related to women's and infants' health being conducted at the U.S. Department of Health and Human Services for fiscal year 2020. SMFM urges Congress to ensure that the Centers for Medicare and Medicaid Services (CMS), Centers for Disease Control and Prevention (CDC), National Institutes of Health (NIH), Health Resources and Services Administration (HRSA) and Agency for Healthcare Research and Quality (AHRQ) are adequately funded in fiscal year 2020. Specifically, we urge the Committee to support a total of $41.6 billion for the NIH, with $1.6 billion of that total to fund the Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD), $7.8 billion for the CDC, $8.56 billion for the Health Services and Resources Administration (HRSA), including $698 million for the Maternal and Child Health Block Grant program, $175 million for the National Center for Health Statistics (NCHS), $460 million for AHRQ, and continued, sustained, broad support for the U.S. Department of Health and Human Services and programs relevant to pregnant and post-partum women and their children.

Established in 1977, SMFM is the medical professional society for obstetricians who have additional training in the area of high-risk, complicated pregnancies. Our members see the sickest and most complex patients, with the goal of optimizing care for pregnant women and their children. The complex problems faced by some mothers may lead to short-term or life-long problems for both mothers and their babies, and in some cases, even death. Such complications can be understood, treated, prevented and eventually solved through research, quality improvement and sustained healthcare with adequate research and public health services.

NATIONAL INSTITUTES OF HEALTH

The Eunice Kennedy Shriver National Institute for Child Health and Human Development (NICHD)'s investment in maternal and child health outcomes is essential to understanding the rising maternal mortality rates and to optimize maternal and child health.

Task Force Specific to Pregnant Women and Lactating Women (PRGLAC): SMFM urges Congress to continue its strong support for the PRGLAC Task Force, housed at NICHD. PRGLAC submitted its report to the Secretary in the fall of 2018 with 15 recommendations on including pregnant women and breastfeeding women in clinical trials and broad research initiatives. We urge Congress to continue to support the implementation of the PRGLAC recommendations. It is essential that Congress support broader inclusion of pregnant and lactating women in research is supported, so that lifesaving interventions and treatments can be addressed for this population.

Preterm Birth: Delivery before 37 weeks' gestation is associated with increased risks of death in the immediate newborn period as well as in infancy and can cause long-term complications. About 20 percent of premature babies die within the first year of life. Although the survival rate is improving, many preterm babies have lifelong disabilities including cerebral palsy, mental retardation, respiratory problems, and hearing and vision impairment. Preterm birth costs the U.S. $32.5 billion annually. Great strides are being made through NICHD-supported research to address the complex situations faced by mothers and their babies. One of the most successful approaches for testing research questions is the NICHD research networks which allow researchers from across the country to collaborate and coordinate their work to change the way we think about pregnancy complications and change medical practice across the country. These networks deal with different aspects of pregnancy the problem of preterm birth and its consequence.

Maternal-Fetal Medicine Units Network (MFMU): We urge continued strong support of the MFMU, established in 1986 to achieve a greater understanding and pursue development of effective treatments for the prevention of preterm births, low birth weight infants and medical complications during pregnancy. We hope that the NICHD will leverage the MFMU to build on its success by ensuring its highly efficient structure of multicenter collaborative research. The MFMU has a strong history of changing and improving clinical practice and obstetric management, improving outcomes of pregnant women and babies in the United States, and is extremely successful, as 25.6 percent of all publications from the network are cited in clinical practice guidelines. These guidelines are relied upon by Medicaid and Medicare programs to define evidence-based services covered under the plans. The work of the network is even more urgent given the increase in maternal mortality and severe morbidity in the US. We urge Congress to ensure stable and sustained funding and infrastructure for the MFMU, and to ensure that any proposed change in the funding mechanism or structure for the MFMU not compromise the ability of the network to remain nimble and directly address the changing landscape of women's health, including to reduce health disparities.

CENTERS FOR DISEASE CONTROL AND PREVENTION

CDC's Division of Reproductive Health (DRH) as well as the National Center for Birth Defects and Developmental Disabilities (NCBDDD) are doing important work related to pregnant mothers. The data collection efforts related to pregnancy outcomes, maternal mortality and medications in pregnancy must continue. The support from CDC to States related to data collection and especially maternal mortality review committees will go a long way toward tackling this growing public health problem. An estimated 700 to 900 women in the U.S. died from pregnancy-related causes in 2016, and that number is only rising. SMFM fully supports Congress' attention to reducing maternal mortality through CDC's Safe Motherhood Initiative, supporting the highest possible allocation for this work. Funding for maternal mortality review committees (MMRCs), perinatal quality collaboratives (PQCs), and other initiatives that would investigate and transparently report on maternal mortality causes while reducing health disparities are essential in tackling our nation's rising maternal mortality rates.

HEALTH RESOURCES AND SERVICES ADMINISTRATION

The work of HRSA is critical to maternal and child health. HRSA's initiatives reduce infant mortality, improve maternal health and wellbeing, and serve more than 50 million people through the MCH block grant. The MCH block grant is critical to ensure that women and their children have access to quality care. These funds provide and ensure access to comprehensive prenatal and postnatal care to women—especially low income and at-risk pregnant women. The Title V MCH Block Grant programs save Federal and State Governments money by ensuring delivery of preventive services to avoid more costly chronic conditions later in life. Additionally, HRSA's family planning initiatives ensure access to comprehensive family planning and preventive health services for more than 4 million people, thereby reducing unintended pregnancy rates. Finally, HRSA's support for the Alliance for Innovation in Maternal Health Care (AIM) reduces maternal mortality through implementation of care bundles at the State and institutional level. These bundles maternal mortality through quality improvement in various areas including postpartum hemorrhage and hypertension. We encourage Congress' support for this important program that will help reduce maternal mortality nationally.

AHRQ

Projects conducted at the Agency for Healthcare Research and Quality (AHRQ) are critical to ensuring that research is translated from bench to bedside through comprehensive implementation in the everyday practice of medicine. Unfortunately, over the past decade, AHRQ's existence has been under threat. AHRQ is the only Federal agency that funds research on "real-life" patients—those with comorbidities and co-existing conditions, including high-risk pregnant women are included. In 2000, an estimated 60 million Americans had multiple chronic conditions. By 2020, an estimated 81 million people will have multiple chronic conditions, and the costs of their care will consume 80 percent of publicly funded health insurance programs, such as Medicare and Medicaid. Unfortunately, the $30 million cut AHRQ sustained in fiscal year 2016 resulted in the termination of the agency's portfolio aimed at optimizing care for patients with multiple chronic conditions. Restoring AHRQ's budget to the fiscal year 2010 level of $454 million will support research to supply providers with the tools they need to best serve these patients. SMFM urges the Committee to ensure that AHRQ is prioritized in fiscal year 2010 to ensure that medical progress into better care for patients today.

CONCLUSION

With your support of vital HHS programs, researchers, clinicians and patients can continue to peel away the layers of complex problems of pregnancy that have such devastating consequences and truly improve the health and wellbeing of mothers and babies.

[This statement was submitted by Dr. Brian Iriye, President, Society for Maternal-Fetal Medicine.]

PREPARED STATEMENT OF THE SOCIETY FOR NEUROSCIENCE

Ms. Chair and members of the Subcommittee, I am Diane Lipscombe, President of the Society for Neuroscience (SfN) and it is my honor to present this testimony on behalf of the Society in strong support of at least a $2.5 billion increase in funding for the National Institutes of Health (NIH), to $41.6 billion, for fiscal year 2020, including the release of the 21st Century Cures funding. I am offering this testimony in my capacity as President of SfN, an association, now entering its 50th year, of nearly 37,000 neuroscientists from all 50 States and around the world.

As a neuroscience researcher and Director at The Carney Institute for Brain Science at Brown University, I see the importance of Federal funding for neuroscience research daily. In my laboratory, funding from NINDS and NIMH advances our understanding of brain function in normal and disease States, including chronic pain and psychiatric illnesses. Sharing the tools developed in our lab, and our discoveries, speeds the development of new therapies to address unmet clinical needs. Basic research is essential to find ways to diagnose, treat, and cure neurological and psychiatric disorders. This requires contributions from many fields including biology, engineering, mathematics, and medicine; and continuing to attract young scientists is necessary to maintain momentum and our lead position in biomedical research and discovery.

SfN knows the power of the research continuum and that basic scientists generate clinical innovations leading to translational uses impacting public health. Basic research is the foundation upon which all health advances are built, and the future of this research depends on reliable, sustained funding from Congress. SfN is grateful to Congress for recent appropriation increases to NIH. Growing the NIH budget from $30.1 billion to $39.1 billion over 4 years is the sustained effort that is needed, returning economic and health benefits for years to come.

SfN stands with the biomedical research community seeking an increase in NIH funding of at least $2.5 billion above the final fiscal year 2019 level, including the release of the 21st Century Cures funding. Moreover, SfN urges Congress to provide relief from the draconian cuts set to take effect as a result of the Budget Control Act (BCA). By raising the BCA caps, Congress can ensure that we do not backslide on previous support for scientific research and discoveries. Concurrently, our funding request continues the support provided by this Committee and ensures predictability and stability to scientists relying on Federal funding.

Equally important to providing a reliable increase in Federal funding for biomedical research is completing appropriations by September 30. Your success in completing NIH appropriations prior to the start of the fiscal year for fiscal year 2019 translated to a tremendous benefit to scientific progress. Reliance on Continuing Resolutions (CR) in place of regular appropriations has critical implications for science, as CRs severely restrict NIH's ability to fund basic neuroscience research. For some SfN members, particularly early career researchers, this meant waiting for a final decision on fiscal year 2018 funding before knowing if their highly meritorious grant applications would be funded. These uncertainties have real and negative impacts on the research being done in the lab by undermining the positive benefits that the research enterprise provides to this country, and by disincentivizing our best young scientists from pursuing research careers.

As a neuroscientist previously funded by the Brain Research through Advancing Innovative Neurotechnologies (BRAIN) Initiative, I appreciate Congress's support, as it prioritizes technology development to learn about human brain function from children to adults. While only a part of the neuroscience research landscape, the BRAIN Initiative is crucial for future discoveries and innovative solutions. By including funding in the 21st Century Cures Act, only part of the BRAIN Initiative's needed funding, Congress is advancing this endeavor. However, using those funds to supplant regular appropriations is counterproductive. There is no substitute for robust, sustained, and predictable funding for NIH-supported research.

The more we know about the basic mechanisms that underlie brain function, the faster we will advance clinical and translational solutions for neurological disorders. In this field, we apply a range of powerful technologies and animal models not used elsewhere in the research pipeline that have the potential for broad impact. Our discoveries, sometimes unexpected, advance basic knowledge of brain function and reveal new therapeutic targets to treat brain disorders affecting millions of people around the world.

As the leading scientific society seeking to understand the brain and nervous system, SfN has great impact and reach within and across disciplines. We host one of the largest annual scientific meetings, disseminate discoveries through highly-rated scientific journals, offer extensive educational programming to raise public awareness of brain research, and engage policymakers in the tremendous progress made in neuroscience research. We are extremely encouraged by the pace of discovery in neuroscience and the promise it offers for future treatments of neurological disorders. Some recent, exciting advancements include the following:

THE IMPACTS OF NEUROSCIENCE RESEARCH

Treatments for Patients with Movement Disorders

One breakthrough in neuroscience, thanks to Federal funding from NINDS, benefits patients with Spinal Muscular Atrophy (SMA), the most common genetic disorder linked to infant death worldwide. SMA impacts the brain stem and spinal cord and hinders the ability to achieve motor milestones and mobility. Recent clinical trials using a new therapy is recovering motor movements in infants with SMA, improving their head control, crawling, walking, and sitting. This form of therapy may also benefit those suffering from motor dysfunctions, such as Parkinson's, Lou Gehrig's, and Huntington's diseases. The basic research critical for this treatment goes back 25 years, but its potential impact will likely extend far into the future.

Regulation of Neuronal Communication

My research seeks to understand how neurons communicate with each other. Brain function is defined by neurons communicating information from cell to cell, and from one brain region to another. Communication between neurons is carried across spaces called synapses by neurotransmitters. The number of neurotransmitters available to transmit these signals is controlled by "gatekeepers," which ensure appropriate size responses. Many therapeutic drugs used in the clinic act on these molecular gatekeepers to dial up or down the flow of communication in the brain. I describe the basic properties of gatekeepers and show how they are generated in specific neurons of the brain and nervous system. My work is basic in nature, but these findings are used to inform the development of new therapeutics for treating major neurological diseases, including chronic pain, migraine, epilepsy, and neuropsychiatric disorders.

Imaging to Understand Brain Function and Disease

The BRAIN Initiative has generated new tools and technologies that researchers can use to visualize brain activity, including watching networks of brain cells interact to control behavior. Such advances will allow us to describe both normal brain function and understand what goes wrong in brain disease. Until now, most methods used to visualize a functioning brain caused severe tissue damage. Two-photon excitation microscopy revolutionized neuroscience in its ability to view neuronal activity in a living brain tissue with very limited tissue damage. This technique also allows us to look at the brain in much more detail with high resolution to detect the points of connection—synapses—as signals move from one part of the brain to the other. This, and other powerful imaging approaches, are being combined to follow and detect abnormal neuronal communication in the brain with unparalleled resolution. If we can localize abnormal activity to specific brain regions, we can devise methods to correct abnormalities in communications between neurons, features of several neurological disorders.

SUMMARY AND CONCLUSION

NIH funding is critical for the future of biomedical research and for training young researchers at the bench, as well as a major driver of the United States economy. While our Nation is the global leader, other countries are also investing increasing amounts into biomedical research. Congress must continue to support basic research in order to fuel scientific discoveries, maintain our preeminence as a leader in the field, and continue to drive the United States' economy into the future. Nearly one in five US adults live with mental illness, early childhood stress has lasting impacts through adulthood, and the growth of age-related neurological disorders is still increasing. The only way to change the trajectory of neurological and psychiatric disorders is to increase Federal Government investment in biomedical research.

SfN strongly supports at least $41.6 billion for the National Institutes of Health for fiscal year 2020, including the release of the 21st Century Cures Act funding. Like the Subcommittee, SfN also supports continuing regular order and avoiding disruptive interruptions to biomedical research.

On behalf of SfN, I would like to thank Congress for its commitment and continued support of neuroscience research. Congress, the NIH, and the scientific research community must continue to collaborate to assist those suffering from diseases, disorders, and injuries of the brain and nervous system. Thank you for this opportunity to testify.

[This statement was submitted by Diane Lipscombe, PhD, President, Society for Neuroscience.]

PREPARED STATEMENT OF THE SPINA BIFIDA ASSOCIATION

Distinguished Committee Members thank you for the opportunity to provide you with testimony of my experiences as a person living with Spina Bifida. My name is Donna Jones and I am here to represent the Spina Bifida Association. We are requesting $8 million dollars for the National Spina Bifida Program, housed at the National Center on Birth Defects and Disabilities at the Centers for Disease Control and Prevention.

As a former Capitol Hill staffer, I understand how essential committee hearings are to the appropriations process.

When I was born on the island of Guam in 1976 the doctors told my parents, "She will never walk, never talk, and will be a vegetable the rest of her life. You already have one healthy daughter; you should focus on her and institutionalize the other one, just walk away." This April 20th, I will be 43 years old. I love birthdays because with every passing year I defy all the negative predictions about what my life would be. I am happy to say I'm part of the first generation to survive to adulthood. The big obstacle to this is that adult care doctors do not have protocols in place to treat our myriad of issues. Most have never had a patient with Spina Bifida. The majority of the Spina Bifida population remain under the care of multiple pediatric specialists, these doctors are the only ones who have treated a large number of us. I may never transition to adult care.

Under the auspices of the Centers for Disease Control and Prevention, the National Center for Birth Defects and Developmental Disabilities and the Spina Bifida Association have developed the National Spina Bifida Patient Registry. The registry stores data on patients from 24 Spina Bifida clinics in the United States. Its primary purpose is to collect information on health issues patients are experiencing, the treatment they received, and will ultimately be studied to determine the effectiveness of the treatment. My medical information is part of the Registry. My doctors at Duke University run a stellar program for treating patients with Spina Bifida, and I hope my medical history will help develop sound medical treatments so people with Spina Bifida can live longer, healthier, lives. Even though I live in California, I travel to the Duke University Pediatric Spina Bifida clinic to receive care. I'm lucky that I can afford this luxury.

I don't live in fear of my Spina Bifida, but, as I age, I do worry about my urologic issues. The majority of people with Spina Bifida are incontinent of bladder and bowel. I do my best to keep my bladder and kidneys healthy. I drink a lot of water, I catheterize myself regularly, and I have yearly check-ups with my urologist. I've had more bladder infections than I can count, and some have sent me to the hospital. Now, the medicine I take to control my bladder spasms is no longer working, and this leaves me vulnerable to bladder infections. I have multiple friends who developed a bladder infection, that spread to their shunts, and they died as a result. I've also had friends who died very quickly from kidney failure. Typical of my fellow Spina Bifida community members, kidney failure, is my greatest concern.

Like 80 percent of people with myelomeningocele (the most common and most severe type of Spina Bifida), I have a pump, called a shunt, installed in my head that drains cerebral spinal fluid off of my brain. My shunt is basically my second heart, I cannot live without it. Excess fluid on the brain, called hydrocephalus, is incredibly dangerous. It can lead to irreparable brain damage or death if not treated. Unfortunately, there is nothing that I can do to keep my shunt functioning. I am basically at its mercy, and if it does malfunction, I need brain surgery to have it replaced. The recovery from shunt revision is long and painful, I count myself lucky that I have only had 14 shunt revisions throughout my life. I have friends, younger than I, who have endured 50 shunt revisions. But, as a result of my many shunt revisions, I have developed seizures caused by scarring on the brain. I take very powerful anti-seizure medicines to keep them under control, and I'm happy to say this medicine is working very well.

I know I have painted a bleak picture of my life and that of my friends with Spina Bifida. It was not my intention to shock you. The truth is, I don't sit at home bemoaning my health problems, and I absolutely do not allow myself to be sorry that I have Spina Bifida. I am too busy training in Los Angeles to break the woman's US bench press record, June 28th of this year. The current record stands at 242 pounds, I intend to break the record with a 260-pound lift. My best bench press so far has been 235 pounds. I have a long way to go; however, I am determined to break this record. Just as exciting my trainer was approached by a producer, who wanted to film a documentary about my journey to break the record, as well as the Spina Bifida community. We started filming as soon as I arrived in Los Angeles. Finally, I have been using a wheelchair for the last 6 years, but I am now taking physical therapy because I am determined to walk again.

I don't ever want anyone to pity me, I have a wonderful life. I truly believe I am not a mistake and I was born with Spina Bifida for a reason. I'm very blessed to have only three surgeries in the last 6 years. I am doing extremely well, I love who I am as a person with a disability, I have zero regrets. That being said, I hope to see in my lifetime a cure for Spina Bifida. As much as I love my life, do I want another child with Spina Bifida to have 32 surgeries as I've had or 60 surgeries like some of my friends? No, I do not want that.

My dear friend and mentor, Tom Baroch, died last November at the age of 58. I miss him more every day, but I take comfort in knowing he didn't die of a Spina Bifida related problem. He died from a blood clot, like so many other people who don't have Spina Bifida. Tom got to grow old with Spina Bifida. I know most adults don't consider 58 as old. By Spina Bifida standards I am old as was Tom. My neurosurgeon jokingly tells me every time I see him, "Now try to behave, Donna, because you are old with Spina Bifida." He is right, I am old, but I want the opportunity to grow old enough to look in the mirror and see wrinkles on my face and more gray hairs on my head than I can count. This is a dream I never allowed myself to have until I was in my 30's. I respectfully ask you to increase funding for the National Spina Bifida Patient Registry as well as additional funding for a hydrocephalus protocol development. These funds will help those who come after me live healthier lives and help us all live long enough to see wrinkles on our faces.

Thank you again for this great honor of giving my testimony. I hope I have shed light on the value of increasing funding for the great work that currently is being done by the CDC, it has a direct effect on my life and that of my community.

Thank you.

PREPARED STATEMENT OF TEACH FOR AMERICA—CALIFORNIA

Thank you for the opportunity to submit testimony on the importance of Federal funding for evidence-based teacher training and recruitment programs at the U.S. Department of Education and the Corporation for National and Community Service in fiscal year 2020. As the Executive Directors of Teach For America's four California regions we are pleased to share the impact that Federal funding has on our mission.

Teach For America (TFA) is a national non-profit that finds, develops, and supports a diverse network of leaders who expand opportunity from classrooms, schools, and every sector and field that shapes the broader systems in which schools operate.

Since 1990, TFA has placed and supported nearly 60,000 teachers in high-need schools throughout the country, with about two-thirds of our alumni continuing to work in education. Today, we have a corps of nearly 6,700 teachers in 51 urban and rural regions in 36 States and the District of Columbia.

In California, over 700 corps members teach in almost 300 schools impacting over 64,000 students across the State. TFA teachers work in the highest-poverty schools and the hardest-to-staff subject areas, including STEM and English as a Second Language (ESL). In addition, TFA teachers are one and a half times more diverse as California's general teaching population with 61 percent of corps members identifying as a person of color. Every day these teachers are proving that with hard work, determination, and partnerships across the community, all students can achieve at the highest levels.

With nearly 29 years of experience in recruiting and training teachers, our model is among one of the most rigorously evaluated teacher preparation and leadership development programs in the country. We rely on external researchers to analyze, validate, and identify opportunities to improve our programmatic model. A growing body of the most rigorous research demonstrates that our corps members and alumni are making a positive impact on students, and we continue to seek additional data to further strengthen our work.

We believe that the Federal Government should prioritize its support for programs with evidence of effectiveness, and applaud the Committee's commitment to results-driven initiatives.

I would like to highlight several of these programs and ask for your continued support in fiscal year 2020.

Corporation for National and Community Service (AmeriCorps): $1.1 B/$425 Million

Since 1994, more than 1 million individuals—including TFA corps members—have served through national service programs like AmeriCorps.

Together, these individuals have provided more than 1.4 billion hours of service to tackle the toughest problems in our communities. Unfortunately, many individuals who want to serve, particularly as educators, face significant economic barriers, including high student debt and the cost of teacher certification, which make it difficult to enter a lower-paying profession such as teaching. This is no different for TFA corps members.

Fortunately, our teachers can use the AmeriCorps Education Award to pay for college tuition or to pay down student debt. This award also enables TFA corps members to defer their undergraduate loans for the first 2 years of teaching and have the interest, which accrues during those 2 years, paid off by the Federal Government. Without this award, we would not be able to attract such a diverse and high caliber leadership force, leaders who stay in California after their corps commitment and lead at all levels, like our regions' 2,5000+ alumni teachers, 250+ alumni school administrators, and 65 school system leaders. Leaders like Alma Delia, a 2012 Los Angeles corps member, who was elected to the Lynwood School Board in 2013, where she has made college accessibility and readiness a main priority. Alma also serves as a digital learning instructional coach for El Rancho Unified School District, she completed her master's degree in Urban Education at Loyola Marymount University, and looks forward to continuing her involvement in the college access movement.

These education awards make it possible for people from all walks-of-life to join TFA and many other AmeriCorps partner programs. TFA's partnership with AmeriCorps has helped put tens of thousands of quality educators in low-income urban and rural areas and developed a diverse pipeline of leadership for our country. In fact, in 2018, our incoming TFA corps was about 50 percent people of color compared to less than 20 percent of teachers of color nationwide. In addition, one-third of corps members were the first in their family to attend college and nearly 45 percent received Pell Grants.

DEPARTMENT OF EDUCATION

Supporting Effective Educator Development (SEED): $94 Million in Fiscal Year 2020

TFA corps members receive 2 years of ongoing training and support to prepare them to teach in low-income, high-need schools. The SEED grant has supported this training by funding TFA's teacher-training institutes, which all corps members must complete before they enter their classrooms.

The education landscape has changed dramatically since TFA sent its first cohort of teachers into the classroom 29 years ago. SEED support has been critical to adjusting our training to meet the needs of students and to align with what States and school districts need of their teachers.

With the support of a 2013 SEED Grant, TFA launched its first regional training institutes in 2014. These new institutes allowed regions to build out their own locally driven teacher preparation in which teachers receive training and teach summer school in the same communities where they will serve. By tailoring training to the specific needs of individual communities, we were able to expand learning opportunities for local students, while also developing teachers who were familiar with and invested in their local communities.

With the help of continued SEED funding in 2015 and 2017, TFA has expanded from two regional institutes in 2014 to 13 in 2018. In addition, five of our regions that serve predominantly rural communities worked together to launch the Delta Collective Summer Institute in Mississippi. Having a training experience grounded in the unique needs and assets of rural communities will continue to help foster a corps of teachers who are more engaged and invested in their rural communities and can serve students living in these communities more effectively.

The 2015 passage of the bipartisan Every Student Succeeds Act (ESSA) expanded SEED eligibility to institutions of higher education engaged in national work, which is why it is important that SEED funding is restored to the fiscal year 2016 level of $94 million. In competitions run by the Department of Education after ESSA, of the 24 grants awarded, only 6 (25 percent) of the awards went to national non-profits and 18 (75 percent) of the awards went to IHEs.

Furthermore, under a pre-ESSA competition in 2015, the Department of Education awarded 13 new grants (all non-profits), impacting over 50,000 educators serving 7.8 million students. In 2017, the Department of Education reported that SEED grants under this first ESSA competition would only reach about 17,000 teachers and 3,000 principals. In 2018, the Department of Education reported that SEED grants would reach “more than 12,000 teachers and 1,300 principals”.

The apparent reduction in impact is troubling and it is my hope that the Committee will direct the Secretary to ensure that grants are distributed among eligible entities operating programs of national significance and supporting a significant number of educators in multiple States and sites to ensure the maximum number of educators and students across the country are served.

Education, Innovation and Research (EIR): $130 Million

Education Innovation and Research (EIR) grants support new methods to improve student achievement, increase high school graduation rates, and improve college enrollment and completion. EIR is unique, as it requires projects to have a promising model and/or high evidence of effectiveness in order to win. In addition, grantees must fund an independent evaluation.

Through a 2010 EIR Expansion grant, TFA was able to pilot new strategies to attract a more racially and socioeconomically diverse corps of teachers. In the first year of the grant, 34 percent of the 2011 corps identified as people of color, 30 percent came from low-income backgrounds, and 22 percent reported being the first in their family to graduate from college. In the last year of the grant, nearly half of the 2015 corps identified as people of color, 47 percent come from low-income backgrounds, a third report being the first in their family to graduate from college. In addition, by 2015, 20 percent of corps members had a background in science, technology, engineering, or math (STEM).

Through a 2017 Early Phase grant, TFA expanded its Rural School Leadership Academy (RSLA) to serve more than 250 school leaders in rural communities over the next 5 years. The RSLA is a 1 year professional development program focused on growing the skills and mind-sets necessary for individuals to become school leaders in rural communities. The RSLA not only represents important professional development for rural teachers, this program is a key tool in our work to retain great talent in rural communities across the country.

Over the last 5 years, the U.S. Department of Education received nearly 5,000 applications but made only 156 grants. This is a total application-success rate of only 3.1 percent. Given this demand from the education field and EIR’s focus on supporting programs with evidence of effectiveness, we believe that maintaining this funding is a wise investment.

The President’s fiscal year 2020 budget proposal would limit the program’s focus on two priorities: teacher training and STEM activities. While both are laudable priorities, limiting the focus of this specific program undermines the original intent of EIR, as authorized by ESSA, which is to support a number of diverse and innovative programs throughout the country. It is my hope that the Committee will ensure that funds appropriated for EIR continue to support diverse and field-initiated interventions, rather than a single nationwide program or awards focused solely on one area of educational innovation.

CONCLUSION

Again, thank you for the opportunity to share these priorities. I appreciate the challenges that the Committee faces in setting funding levels across a multitude of worthy programs, and I look forward to working with you to meet the needs of America's students and teachers.

PREPARED STATEMENT OF TEACH FOR AMERICA—GREATER DELTA

Thank you for the opportunity to submit testimony on the importance of Federal funding for evidence-based teacher training and recruitment programs at the U.S. Department of Education and the Corporation for National and Community Service in fiscal year 2020. As the former Executive Director of Teach For America-Delta for 18 years and now the Deputy ED these past 5 years, I am pleased to share the impact that Federal funding has on our mission.

Teach For America (TFA) is a national non-profit that finds, develops, and supports a diverse network of leaders who expand opportunity from classrooms, schools, and every sector and field that shapes the broader systems in which schools operate.

Since 1990, TFA has placed and supported nearly 60,000 teachers in high-need schools throughout the country, with about two-thirds of our alumni continuing to work in education. Today, we have a corps of nearly 6,700 teachers in 51 urban and rural regions in 36 States and the District of Columbia.

Teach For America began placing teaches in Arkansas in 1991, then expanded into Mississippi in 1993. Over those 28 years, TFA partnered with local communities and districts, and placed a total of 1,074 teachers in Arkansas classrooms and 1,949 teachers in Mississippi schools. These 3,023 teachers have collective taught some 200,000 children Pre-K—12 and in almost every subject offered. Last year in Mississippi, students in TFA classrooms on-average grew 1.33 years in their respective grade or subject. And as a comparison, when I joined TFA as ED in 1996 we had 5 individuals who had remained beyond their initial 2-year commitment. Currently, some 500 TFA alumni (3–28 years after starting the corps) are living and leading in various sectors within our bi-State region, and 75 percent of that number remain in some field of education, including 3 State Teachers-of-the-Year, 10 professors, 2 Superintendents, over a dozen school leaders, and the vast majority are career classroom teachers.

With nearly 29 years of experience in recruiting and training teachers, our model is among one of the most rigorously evaluated teacher preparation and leadership development programs in the country. We rely on external researchers to analyze, validate, and identify opportunities to improve our programmatic model. A growing body of the most rigorous research demonstrates that our corps members and alumni are making a positive impact on students, and we continue to seek additional data to further strengthen our work.

We believe that the Federal Government should prioritize its support for programs with evidence of effectiveness, and applaud the Committee's commitment to results-driven initiatives.

I would like to highlight several of these programs and ask for your continued support in fiscal year 2020.

Corporation for National and Community Service (AmeriCorps): $1.1 B/$425 Million

Since 1994, more than 1 million individuals—including TFA corps members—have served through national service programs like AmeriCorps.

Together, these individuals have provided more than 1.4 billion hours of service to tackle the toughest problems in our communities. Unfortunately, many individuals who want to serve, particularly as educators, face significant economic barriers, including high student debt and the cost of teacher certification, which make it difficult to enter a lower-paying profession such as teaching. This is no different for TFA corps members.

Fortunately, our teachers can use the AmeriCorps Education Award to pay for college tuition or to pay down student debt. This award also enables TFA corps members to defer their undergraduate loans for the first 2 years of teaching and have the interest, which accrues during those 2 years, paid off by the Federal Government. Given the tremendous and chronic need for teachers in our two-State region, the Education Award helps us attract more talent to our region. As college tuition and student debt continues to soar, the Awards have made it possible for highly desired, top-notch talent to teach in our region. It has especially helped us diversify and attract ever greater numbers of low-income, racially diverse, and in-State talent in our Greater Delta corps. This year, 48 percent of our incoming Greater Delta Corps had received Pell Grants in college and 34 percent self-identified as Individuals of Color.

These education awards make it possible for people from all walks-of-life to join TFA and many other AmeriCorps partner programs. TFA's partnership with AmeriCorps has helped put tens of thousands of quality educators in low-income urban and rural areas and developed a diverse pipeline of leadership for our country. In fact, in 2018, our incoming TFA corps was about 50 percent people of color compared to less than 20 percent of teachers of color nationwide. In addition, one-third of corps members were the first in their family to attend college and nearly 45 percent received Pell Grants.

DEPARTMENT OF EDUCATION

Supporting Effective Educator Development (SEED): $94 Million in Fiscal Year 2020

TFA corps members receive 2 years of ongoing training and support to prepare them to teach in low-income, high-need schools. The SEED grant has supported this training by funding TFA's teacher-training institutes, which all corps members must complete before they enter their classrooms.

The education landscape has changed dramatically since TFA sent its first cohort of teachers into the classroom 29 years ago. SEED support has been critical to adjusting our training to meet the needs of students and to align with what States and school districts need of their teachers.

With the support of a 2013 SEED Grant, TFA launched its first regional training institutes in 2014. These new institutes allowed regions to build out their own locally driven teacher preparation in which teachers receive training and teach summer school in the same communities where they will serve. By tailoring training to the specific needs of individual communities, we were able to expand learning opportunities for local students, while also developing teachers who were familiar with and invested in their local communities.

With the help of continued SEED funding in 2015 and 2017, TFA has expanded from two regional institutes in 2014 to 13 in 2018. In addition, five of our regions that serve predominantly rural communities worked together to launch the Delta Collective Summer Institute in Mississippi. Having a training experience grounded in the unique needs and assets of rural communities will continue to help foster a corps of teachers who are more engaged and invested in their rural communities and can serve students living in these communities more effectively.

The 2015 passage of the bipartisan Every Student Succeeds Act (ESSA) expanded SEED eligibility to institutions of higher education engaged in national work, which is why it is important that SEED funding is restored to the fiscal year 2016 level of $94 million. In competitions run by the Department of Education after ESSA, of the 24 grants awarded, only 6 (25 percent) of the awards went to national non-profits and 18 (75 percent) of the awards went to IHEs.

Furthermore, under a pre-ESSA competition in 2015, the Department of Education awarded 13 new grants (all non-profits), impacting over 50,000 educators serving 7.8 million students. In 2017, the Department of Education reported that SEED grants under this first ESSA competition would only reach about 17,000 teachers and 3,000 principals. In 2018, the Department of Education reported that SEED grants would reach "more than 12,000 teachers and 1,300 principals".

The apparent reduction in impact is troubling and it is my hope that the Committee will direct the Secretary to ensure that grants are distributed among eligible entities operating programs of national significance and supporting a significant number of educators in multiple States and sites to ensure the maximum number of educators and students across the country are served.

Education, Innovation and Research (EIR): $130 Million

Education Innovation and Research (EIR) grants support new methods to improve student achievement, increase high school graduation rates, and improve college enrollment and completion. EIR is unique, as it requires projects to have a promising model and/or high evidence of effectiveness in order to win. In addition, grantees must fund an independent evaluation.

Through a 2010 EIR Expansion grant, TFA was able to pilot new strategies to attract a more racially and socioeconomically diverse corps of teachers. In the first year of the grant, 34 percent of the 2011 corps identified as people of color, 30 percent came from low-income backgrounds, and 22 percent reported being the first in their family to graduate from college. In the last year of the grant, nearly half of the 2015 corps identified as people of color, 47 percent come from low-income backgrounds, a third report being the first in their family to graduate from college. In addition, by 2015, 20 percent of corps members had a background in science, technology, engineering, or math (STEM).

Through a 2017 Early Phase grant, TFA expanded its Rural School Leadership Academy (RSLA) to serve more than 250 school leaders in rural communities over the next 5 years. The RSLA is a 1 year professional development program focused on growing the skills and mind-sets necessary for individuals to become school leaders in rural communities. The RSLA not only represents important professional development for rural teachers, this program is a key tool in our work to retain great talent in rural communities across the country.

Over the last 5 years, the U.S. Department of Education received nearly 5,000 applications but made only 156 grants. This is a total application-success rate of only 3.1 percent. Given this demand from the education field and EIR's focus on supporting programs with evidence of effectiveness, we believe that maintaining this funding is a wise investment.

The President's fiscal year 2020 budget proposal would limit the program's focus on two priorities: teacher training and STEM activities. While both are laudable priorities, limiting the focus of this specific program undermines the original intent of EIR, as authorized by ESSA, which is to support a number of diverse and innovative programs throughout the country. It is my hope that the Committee will ensure that funds appropriated for EIR continue to support diverse and field-initiated interventions, rather than a single nationwide program or awards focused solely on one area of educational innovation.

CONCLUSION

Again, thank you for the opportunity to share these priorities. I appreciate the challenges that the Committee faces in setting funding levels across a multitude of worthy programs, and I look forward to working with you to meet the needs of America's students and teachers.

PREPARED STATEMENT OF TEACH FOR AMERICA—OKLAHOMA

Thank you for the opportunity to submit testimony on the importance of Federal funding for evidence-based teacher training and recruitment programs at the U.S. Department of Education and the Corporation for National and Community Service in fiscal year 2020. As the Executive Directors of Teach For America—Oklahoma City & Teach For America—Greater Tulsa, we are pleased to share the impact that Federal funding has on our mission.

Teach For America (TFA) is a national non-profit that finds, develops, and supports a diverse network of leaders who expand opportunity from classrooms, schools, and every sector and field that shapes the broader systems in which schools operate.

Since 1990, TFA has placed and supported nearly 60,000 teachers in high-need schools throughout the country, with about two-thirds of our alumni continuing to work in education. Today, we have a corps of nearly 6,700 teachers in 51 urban and rural regions in 36 States and the District of Columbia. Teach For America Oklahoma is building a network of leaders who are expanding opportunities for Oklahoma's children. We begin by recruiting diverse, driven leaders (our corps members) to commit to teach for at least 2 years in some of our highest-need schools in Lawton, Muskogee, Oklahoma City, and Tulsa. Working shoulder-to-shoulder with students, educators, and community members and with the support of our team, corps members go beyond traditional expectations to support the academic and personal growth of their students. The impact corps members have in the classroom fuels a lifelong commitment to their students and shapes the trajectory of their lives and careers. Over the course of our alumni's careers, Teach For America works to support and network them for increasing impact.

Our network of leaders has impacted more than 100,000 students across Oklahoma since 2009. Today, nearly 250 corps members teachers work in 64 schools, and over 400 Teach For America alumni are working in and contributing to the future of Oklahoma. Over the last decade, Teach For America has placed outstanding teachers in Oklahoma's high need classrooms, and developed exceptional leaders for all these sectors critical to shaping a 21st century educational system: leaders in education, leaders in business/social entrepreneurship, elected officials, and non profit leaders.

With nearly 29 years of experience in recruiting and training teachers, our model is among one of the most rigorously evaluated teacher preparation and leadership development programs in the country. We rely on external researchers to analyze, validate, and identify opportunities to improve our programmatic model. A growing body of the most rigorous research demonstrates that our corps members and alumni are making a positive impact on students, and we continue to seek additional information to further strengthen our work.

We believe that the Federal Government should prioritize its support for programs with evidence of effectiveness, and applaud the Committee's commitment to results-driven initiatives.

I would like to highlight several of these programs and ask for your continued support in fiscal year 2020.

Corporation for National and Community Service (AmeriCorps): $1.1 B/$425 Million

Since 1994, more than 1 million individuals-including TFA corps members-have served through national service programs like AmeriCorps.

Together, these individuals have provided more than 1.4 billion hours of service to tackle the toughest problems in our communities. Unfortunately, many individuals who want to serve, particularly as educators, face significant economic barriers, including high student debt and the cost of teacher certification, which make it difficult to enter a lower-paying profession such as teaching. This is no different for TFA corps members.

Fortunately, our teachers can use the AmeriCorps Education Award to pay for college tuition or to pay down student debt. This award also enables TFA corps members to defer their undergraduate loans for the first 2 years of teaching and have the interest, which accrues during those 2 years, paid off by the Federal Government. In the 2018–2019 academic year alone, four of our alumni were named finalists for the Oklahoma City and Tulsa Public Schools' Teacher of the Year award and more than 20 of our corps members and alums were honored as a school site Teachers of the Year. During her first year of teaching, 83 percent of Mia Philichi's ('17, Oklahoma City) students achieved proficiency on their end of year exam, and 100 percent met proficiency in English Language Arts. Luke Rose ('17 Greater Tulsa), Christian Barrera ('17 Greater Tulsa), and Neal Patel ('17 Greater Tulsa) are also incredible examples of our effective pipeline of educators who have led their students to remarkable success. As the Hale Junior High Teach-to-One Math department, their students grew 1.4 years in the NWEA MAP-Math assessment, a nationally normed and rigorous exam. Their leadership extends outside their classroom, changing the narrative for what students at Hale and Tulsa can accomplish. In fact, their team was recently highlighted by EdWeek, a national education publication, for their work in creating a data-driven "super" team.

These education awards make it possible for people from all walks of life to join TFA and many other AmeriCorps partner programs. TFA's partnership with AmeriCorps has helped put tens of thousands of quality educators in low-income urban and rural areas and developed a diverse pipeline of leadership for our country. In fact, in 2018, our incoming corps was about half people of color. In addition, one-third of corps members were the first in their family to attend college and nearly 45 percent received Pell Grants.

DEPARTMENT OF EDUCATION

Supporting Effective Educator Development (SEED): $94 Million in Fiscal Year 2020

TFA corps members receive 2 years of ongoing training and support to prepare them to teach in low-income, high-need schools. The SEED grant has supported this training by funding TFA's teacher-training institutes, which all corps members must complete before they enter their classrooms.

The education landscape has changed dramatically since TFA sent its first cohort of teachers into the classroom 29 years ago. SEED support has been critical to adjusting our training to meet the needs of students and to align with what States and school districts need of their teachers.

With the support of a 2013 SEED Grant, TFA launched its first regional training institutes in 2014. These new institutes allowed regions to build out their own locally driven teacher preparation in which teachers receive training and teach summer school in the same communities where they will serve. By tailoring training to the specific needs of individual communities, we were able to expand learning opportunities for local students, while also developing teachers who were familiar with and invested in their local communities. With the help of continued SEED funding in 2015 and 2017, TFA has expanded from two regional institutes in 2014 to 13 in 2018. In addition, five of our regions that serve predominantly rural communities worked together to launch the Delta Collective Summer Institute in Mississippi. Having a training experience grounded in the unique needs and assets of rural communities will continue to help foster a corps of teachers who are more engaged and invested in their rural communities and can serve students living in these communities more effectively.

The 2015 passage of the bipartisan Every Student Succeeds Act (ESSA) expanded SEED eligibility to institutions of higher education, which is why it is important that SEED funding is restored to the fiscal year 2016 level of $94 million. Furthermore, the 2017 SEED grant competition demonstrates a potential unintended consequence of this policy change. Of the ten organizations awarded grants in 2017, 80 percent were institutions of higher education. Based on this, TFA is concerned that the original Congressional intent of SEED may be undermined. As the only Federal funding available to national non-profits for improving teacher quality, SEED was created to support non-profits with a national reach to broaden the impact of research-based teacher preparation and development by bringing it to a national scale. Further, we believe that the only way we can collectively solve for the greatest educational challenges is to promote innovation from a diversity of perspectives across the education field. It is our hope that Congress and the Department of Education can ensure diversity of SEED grantees and balance awards to institutions of higher education and non-profits.

Education, Innovation and Research (EIR): $130 Million in Fiscal Year 2020

Education Innovation and Research (EIR) grants support new methods to improve student achievement, increase high school graduation rates, and improve college enrollment and completion. EIR is unique, as it requires projects to have a promising model and/or high evidence of effectiveness in order to win. In addition, grantees must fund an independent evaluation.

Through a 2010 EIR Expansion grant, TFA was able to pilot new strategies to attract a more racially and socioeconomically diverse corps of teachers. In the first year of the grant, 34 percent of the 2011 corps identified as people of color, 30 percent came from low-income backgrounds, and 22 percent reported being the first in their family to graduate from college. In the last year of the grant, nearly half of the 2015 corps identified as people of color, 47 percent come from low-income backgrounds, a third report being the first in their family to graduate from college. In addition, by 2015, 20 percent of corps members had a background in science, technology, engineering, or math (STEM).

Through a 2017 Early Phase grant, TFA is expanding its Rural School Leadership Academy (RSLA) to serve more than 250 school leaders in rural communities over the next 5 years. The RSLA is a 1 year professional development program focused on growing the skills and mind-sets necessary for individuals to become school leaders in rural communities. The RSLA not only represents important professional development for rural teachers, this program is a key tool in our work to retain great talent in rural communities across the country.

Over the last 5 years, the U.S. Department of Education received nearly 5,000 applications but made only 156 grants. This is a total application-success rate of only 3.1percent. Given this demand from the education field and EIR's focus on supporting programs with evidence of effectiveness, we believe this increase in funding—which is consistent with the President's budget request—is a wise investment.

CONCLUSION

I appreciate the challenges that the Committee faces in setting funding levels across a multitude of worthy programs, and I look forward to working with you to meet the needs of America's students and teachers.

PREPARED STATEMENT OF TEACH FOR AMERICA—SOUTH CAROLINA

Thank you for the opportunity to submit testimony on the importance of Federal funding for evidence-based teacher training and recruitment programs at the U.S. Department of Education and the Corporation for National and Community Service in fiscal year 2020. As the Executive Director of Teach For America-South Carolina I am pleased to share the impact that Federal funding has on our mission.

Teach For America (TFA) is a national non-profit that finds, develops, and supports a diverse network of leaders who expand opportunity from classrooms, schools, and every sector and field that shapes the broader systems in which schools operate.

Since 1990, TFA has placed and supported nearly 60,000 teachers in high-need schools throughout the country, with about two-thirds of our alumni continuing to work in education. Today, we have a corps of nearly 6,700 teachers in 51 urban and rural regions in 36 States and the District of Columbia. The TFA-South Carolina region opened in 2011 and has placed over 1,030 teachers in districts across the Lowcountry, Pee Dee, and Orangeburg regions. We are proud to have served over

53,126 students alongside our incredible community members and partner organizations. On average, since opening our doors in 2011, 27 percent of our incoming corps has had ties to South Carolina.

With nearly 29 years of experience in recruiting and training teachers, our model is among one of the most rigorously evaluated teacher preparation and leadership development programs in the country. We rely on external researchers to analyze, validate, and identify opportunities to improve our programmatic model. A growing body of the most rigorous research demonstrates that our corps members and alumni are making a positive impact on students, and we continue to seek additional data to further strengthen our work.

We believe that the Federal Government should prioritize its support for programs with evidence of effectiveness, and applaud the Committee's commitment to results-driven initiatives.

I would like to highlight several of these programs and ask for your continued support in fiscal year 2020.

Corporation for National and Community Service (AmeriCorps): $1.1 B/$425 Million

Since 1994, more than 1 million individuals—including TFA corps members—have served through national service programs like AmeriCorps.

Together, these individuals have provided more than 1.4 billion hours of service to tackle the toughest problems in our communities. Unfortunately, many individuals who want to serve, particularly as educators, face significant economic barriers, including high student debt and the cost of teacher certification, which make it difficult to enter a lower-paying profession such as teaching. This is no different for TFA corps members.

Fortunately, our teachers can use the AmeriCorps Education Award to pay for college tuition or to pay down student debt. This award also enables TFA corps members to defer their undergraduate loans for the first 2 years of teaching and have the interest, which accrues during those 2 years, paid off by the Federal Government. One of many examples of our leadership theory in action comes from Mr. Brandon Johnson. Originally from North Augusta, Mr. Johnson joined the corps in 2014. He taught for 3 years in Marion County and fostered the academic growth of over 300 middle school students. After the corps, he earned his master's degree from Coastal Carolina University and currently serves as an Assistant Principal in Spartanburg School District 7. Most recently, he completed our competitive Rural School Leadership Academy Fellowship, which provided him specialized training and development to one day lead his own school. Mr. Johnson, like so many of our Teach For America alumni, draws inspiration from a deep belief that all students in South Carolina deserve the opportunity to attain an excellent education.

These education awards make it possible for people from all walks-of-life to join TFA and many other AmeriCorps partner programs. TFA's partnership with AmeriCorps has helped put tens of thousands of quality educators in low-income urban and rural areas and developed a diverse pipeline of leadership for our country. In fact, in 2018, our incoming TFA corps was about 50 percent people of color compared to less than 20 percent of teachers of color nationwide. In addition, one-third of corps members were the first in their family to attend college and nearly 45 percent received Pell Grants.

DEPARTMENT OF EDUCATION

Supporting Effective Educator Development (SEED): $94 Million in Fiscal Year 2020

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The education landscape has changed dramatically since TFA sent its first cohort of teachers into the classroom 29 years ago. SEED support has been critical to adjusting our training to meet the needs of students and to align with what States and school districts need of their teachers.

With the support of a 2013 SEED Grant, TFA launched its first regional training institutes in 2014. These new institutes allowed regions to build out their own locally driven teacher preparation in which teachers receive training and teach summer school in the same communities where they will serve. By tailoring training to the specific needs of individual communities, we were able to expand learning opportunities for local students, while also developing teachers who were familiar with and invested in their local communities.

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Furthermore, under a pre-ESSA competition in 2015, the Department of Education awarded 13 new grants (all non-profits), impacting over 50,000 educators serving 7.8 million students. In 2017, the Department of Education reported that SEED grants under this first ESSA competition would only reach about 17,000 teachers and 3,000 principals. In 2018, the Department of Education reported that SEED grants would reach “more than 12,000 teachers and 1,300 principals”.

The apparent reduction in impact is troubling and it is my hope that the Committee will direct the Secretary to ensure that grants are distributed among eligible entities operating programs of national significance and supporting a significant number of educators in multiple States and sites to ensure the maximum number of educators and students across the country are served.

Education, Innovation and Research (EIR): $130 Million

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Over the last 5 years, the U.S. Department of Education received nearly 5,000 applications but made only 156 grants. This is a total application-success rate of only 3.1 percent. Given this demand from the education field and EIR’s focus on supporting programs with evidence of effectiveness, we believe that maintaining this funding is a wise investment.

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CONCLUSION

Again, thank you for the opportunity to share these priorities. I appreciate the challenges that the Committee faces in setting funding levels across a multitude of worthy programs, and I look forward to working with you to meet the needs of America’s students and teachers.

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 2020. 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 fiscal year 2020 Labor, Health and Human Services (LHHS), Education and Related Agencies Appropriations. The program on Tourette Syndrome is administered within the National Center on Birth Defects and Developmental Disabilities (NCBDDD) at the CDC, in partnership with the TAA. This program was established by Congress in the Children's Health Act of 2000 (PL. 106–310 Title 23) and is the only such program that receives Federal funding for Tourette Syndrome (TS). With your support at the previously enacted level of $2 million, CDC can ensure critically necessary progress continues in the areas of public education, research and diagnosis for TS and Tic Disorders.

The TAA is the premier national non-profit organization working to make life better for all people affected by TS and Tic Disorders. We have served in this capacity for 46 years. Tics are involuntary, repetitive movements and vocalizations. They are the defining feature of a group of childhood-onset, neurodevelopmental conditions known collectively as Tic Disorders and individually as Tourette Syndrome, Chronic Tic Disorder (Motor or Vocal Type), and Provisional Tic Disorder. People with TS and Tic Disorders often have substantial healthcare costs across their lifespan for healthcare visits, special educational services, medication, and psychological and behavioral counseling. In a recent survey conducted by the TAA (2018 TAA Impact Survey: https://tourette.org/research-medical/impact-survey/), 63 percent of parents struggle to cover the high costs of services for their child such as counseling, appointments and tutoring; 34 percent of parents report they lost their job or they are not able to work as often due to the increased caregiver duties of having a child living with TS; and, 18 percent of parents are not able to afford medications and/or desired medical care for their child.

The CDC Tourette Syndrome Website (https://www.cdc.gov/ncbddd/tourette/data.html) on data and statistics states that data suggests roughly 50 percent of children and teens with TS are not diagnosed. Studies including children with both with diagnosed and undiagnosed TS have estimated that 1 out of every 162 children (0.6 percent) have TS. However, these numbers do not include children with Chronic or Provisional Tic Disorders. Based on current research, it is our estimate that the combined total of all school-aged children with TS or another related Tic Disorder is approximately 1-in-100. Diagnosis is often complicated. Among children diagnosed with TS, 86 percent have been diagnosed with at least one additional mental, behavioral, or developmental condition according to the CDC website. These co-occurring conditions include Attention Deficit-Hyperactivity Disorder (ADHD), Obsessive Compulsive Disorder (OCD), Autism, Oppositional Defiance Disorder, anxiety, depression, learning difficulties among others and can significantly impact the lives of those affected by TS. In fact, in TAA's 2018 Impact Survey, 42 percent of children felt that dealing co-occurring conditions was one of the biggest challenges in managing TS. In addition, 32 percent of children and 51 percent of adults have considered suicide or participated in self-harming behaviors. The CDC TS Program works to ensure primary care, family doctors or pediatricians are equipped with the additional knowledge necessary either to diagnose or to refer a patient for optimal treatment.

Education professionals often do not receive detailed instruction on how to assess and accommodate students who may have TS and Tic Disorders. A study published in the Journal of Developmental & Behavioral Pediatrics and written in partnership between the CDC and the Tourette Association of America, "Impact of Tourette Syndrome on School Measures in a Nationally Representative Sample", found children with Tourette were more likely to have an individualized IEP, have a parent contacted about school problems and have incomplete homework as compared to children without Tourette or a Tic Disorder. Additionally, most children with Tourette Syndrome had other mental, behavioral, or emotional disorders or learning and language disorders. In TAA's 2018 Impact Survey, 83 percent of children felt that TS negatively impacted their school experience and education and 69 percent of parents noted their child having an individualized education plan (IEP) or 504 plan in place at their school. Educators spend a significant amount of time with their students providing more opportunities to assess symptoms and behavior over a longer period of time. By increasing their knowledge base and understanding of Tourette Syndrome, Tic Disorders and associated co-morbidities, educators can refer students for medical assessment and can also better serve the needs of this population whose challenges are unique to the disorder. Educators can then begin to work more closely with medical providers to develop effective, individualized education plans.

TS and Tic Disorders are greatly misunderstood and often suffer from misinformation and stigma. For example, coprolalia, the involuntary utterance of obscene and socially unacceptable words and phrases, is an extreme and rare symptom often sensationalized by the media. Less than 10 percent of those diagnosed have this symptom, it is not required for diagnosis, and does not persist in many cases. The CDC TS Public Health, Education and Research Program provides important information on symptoms/diagnostic criteria on their website and through the outreach program educating the public and parents on Tourette Syndrome and Tic Disorders to ensure a better understanding which can lead to better diagnosis, earlier treatment and a better understanding.

Delayed diagnosis or the lack of diagnosis can increase healthcare costs, increase education costs and delay important treatment and therapy for the patient. The AAN recently released guidelines (https://n.neurology.org/content/neurology/92/19/896.full.pdf) on the treatment of Tourette Syndrome and Tic Disorders recommending Comprehensive Behavior Intervention for Tics (CBIT) as a first line treatment. CBIT is a non-medicated treatment consisting of three important components: training the patient to be more aware of his or her tics and the urge to tic; training patients to do competing behavior when they feel the urge to tic; and, making changes to day-to-day activities in ways that can be helpful in reducing tics. CBIT teaches people with TS a set of specific skills they can use to manage their tic urges or behaviors without having to use voluntary suppression. According to a study published in the Journal of the American Medical Association in 2010, “Behavior therapy for children with Tourette disorder: a randomized controlled trial”, there were significant reductions in tic severity and improved ability to function in 52.5 percent of children who underwent CBIT therapy in the study. The CDC Tourette Syndrome Public Health, Education and Research Program strives to increase the understanding and awareness among these critically important medical and education professionals to increase the percentage of school aged children with TS who are diagnosed, improve the timeframe from symptoms to diagnosis and educate them about treatment options like CBIT.

The CDC TS program strives to learn more about TS, who it affects, how symptoms appear and change, if tics are an early indicator for the co-occurring conditions, the impact of TS across the lifespan of patients and identifying factors that relate to better or worse outcomes. Increasing understanding and awareness among the general public, government officials, doctors and educators is extremely important for those 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 2020 for the Tourette Syndrome Public Health Education and Research Program at CDC’s National Center for Birth Defects and Developmental Disabilities at the previously enacted level of $2 million.

PREPARED STATEMENT OF TRUST FOR AMERICA’S HEALTH

Thank you, Chairman Blunt and Ranking Member Murray, for the opportunity to submit testimony on behalf of Trust for America’s Health (TFAH) to the United States Senate Appropriations Subcommittee on Labor, Health and Human Services, and Education, and Related Agencies regarding the fiscal year 2020 appropriations bill.

TFAH is a non-profit, non-partisan organization that promotes optimal health for every person and community, and our research has found that investments in public health can save lives and improve the health of Americans, while also ensuring that our health system is as cost-effective as possible. Specifically, by investing $8.3 billion for the Centers for Disease Control and Prevention (CDC), we can start to make critical improvements and investments for our public health system, which is facing a number of unprecedented challenges.

Nothing reflects the values of a country more than the health of its residents. Sadly, Americans are not as healthy as they could or should be—in large part because we routinely underfund our Nation’s public health system, resulting in paying for treatment in the healthcare system rather than prevention of disease. For example, funding for CDC’s obesity prevention efforts only equal to about 31 cents per person, even though obesity is a national problem that accounts for nearly 21 percent of healthcare spending.[1] Such funding misalignments can be found across health conditions, including chronic disease, substance misuse, and infectious disease.

Every community should be safe from threats to its health, and all individuals and families should have access to high-quality 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 health problems. The U.S. needs a long-term commitment to rebuilding the Nation's public health capabilities—not just to filling some of the more dangerous gaps, but also to ensuring that each community will be prepared, responsive, and resilient when the unexpected occurs.

By substantively and strategically investing in public health programs, we can ensure the American people that our public health system can respond to current and emerging public health challenges. For fiscal year 2020, TFAH urges the Senate Appropriations Committee to prioritize public health and support programs within CDC and the Public Health and Social Services Emergency Fund (PHSSEF), specifically:

EMERGENCY PREPAREDNESS

At a time when natural disasters and outbreaks are occurring with alarming frequency and severity, insufficient investments in public health preparedness compromise Americans' safety.

The Public Health Emergency Preparedness (PHEP) cooperative agreement, the main Federal program that ensures health departments can protect Americans from the effects of health emergencies, is a cornerstone of the Nation's health security. Without PHEP funding, States would not have the resources or infrastructure required to prepare, respond and recover from a public health emergency. Due to PHEP funding, all 50 States have improved in nearly all high priority preparedness capabilities defined by CDC.

The Hospital Preparedness Program (HPP), administered by the Assistant Secretary for Preparedness and Response (ASPR), provides critical funding and technical assistance to healthcare coalitions (HCCs) across the country to meet the disaster healthcare needs of communities. There are 476 HCCs, comprised of public health agencies, hospitals, and emergency management and others, develop and implement healthcare and medical readiness; healthcare and medical response coordination; continuity of healthcare services delivery; and medical surge.

Unfortunately, funding for PHEP has been cut by a third since fiscal year 2003, and funding for HPP has been cut nearly in half. It is not enough to deliver short-term, supplemental funding after a disaster occurs. A proper response requires training, plans and systems that can only be established with consistent, ongoing funds. TFAH-recommended fiscal year 2020 funding levels:

—Public Health Emergency Preparedness (PHEP) Cooperative Agreement—$824,000,000
—Hospital Preparedness Program (HPP)—$474,000,000

ENVIRONMENTAL HEALTH

To effectively and efficiently address public health challenges, data must incorporate environmental impacts on health. Since CDC's National Environmental Public Health Tracking Network began collecting data, grantees have taken over 400 data-driven actions to improve health. Data includes rates of asthma, birth defects, drinking water quality (including Per- and polyfluoroalkyl substances (PFAS)), lead poisoning, flood vulnerability, and community design. State and local health departments use this data to provide targeted resources in communities with environmental health concerns.

Presently, twenty-six States and one city are funded to participate in the Tracking Network. TFAH recommends $40 million to launch the program in at least three more States. With a $1.44 return in healthcare savings for every dollar invested, the Tracking Network is a cost-effective program that examines and combats harmful environmental factors.[2] TFAH-recommended fiscal year 2020 funding levels:

—National Environmental Public Health Tracking Network—$40,000,000

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[1] J. Cawley and C. Meyerhoefer, "The Medical Care Costs of Obesity: An Instrumental Variables Approach," Journal of Health Economics 31, no. 1 (2012): 219–30, doi: 10.1016/j.jhealeco.2011.10.003.

[2] Return on Investment of Nationwide Health Tracking, Washington, DC: Public Health Foundation, 2001.

OBESITY AND CHRONIC DISEASE PREVENTION

While obesity rates have slightly decreased among young, low-income children, national obesity rates remain high and continue to rise. In 2015–2016, 18.5 percent of children and 39.6 percent of adults were obese.[3] While overall obesity rates are still rising, there are pockets of success and progress will be at risk if programs are cut and policies are weakened. Therefore, addressing the obesity epidemic remains imperative for ensuring the health of the Nation.

CDC's Division of Nutrition, Physical Activity and Obesity (DNPAO) is working to decrease obesity and chronic disease in communities across the U.S. DNPAO supports healthy eating, active living, and obesity prevention by creating healthy child care centers, hospitals, schools, and worksites; building capacity of State health departments and national organizations; and, conducting research, surveillance and evaluation studies. Unfortunately, DNPAO only has enough money to implement State Physical Activity and Nutrition Programs in 16 States.

Additionally, the Racial and Ethnic Approaches to Community Health (REACH) program, which is housed under DNPAO, works in 31 communities across the country by employing innovative, community-based, and participatory approaches to develop and implement evidence-based practices, empower communities, and reduce racial and ethnic health disparities.

Funding for the CDC's National Center for Chronic Disease Prevention and Health Promotion in fiscal year 2019 was $127 million lower than funds in fiscal year 2012.[4] To adequately address obesity and chronic disease, we must invest in preventive and culturally appropriate strategies. Funding DNPAO and REACH are potentially cost-saving measures that will save and improve the lives of millions of Americans. TFAH-recommended fiscal year 2020 funding levels:

—Division of Nutrition, Physical Activity and Obesity (DNPAO)—$125,000,000
—Racial and Ethnic Approaches to Community Health (REACH)—$76,950,000

HEALTHY OUTCOMES IN SCHOOLS

We know that fostering healthy behaviors in childhood contributes to healthy outcomes in adulthood. The risks of teen pregnancy, sexually transmitted diseases, and sexual violence lessen with high-quality childhood education.[5] The CDC's Division of Adolescent and School Health (DASH) provides education centering health promotion and disease prevention for less than $10 per student. Through school-based surveillance, data collection, and skills development, DASH collaborates with State and local education agencies to increase access to health services and reduce risky sexual behavior. TFAH-recommended fiscal year 2020 funding levels:

—Division of Adolescent and School Health (DASH)—$50,000,000

OPIOID EPIDEMIC

Opioid misuse is a public health epidemic experienced by too many communities across the country. From 2000 to 2016, more than 600,000 people died from drug overdoses. On average, 115 Americans die every day from an opioid overdose, and if current trends continue, more than 1.6 million deaths will occur by 2025.[6] We simply cannot afford for this rate to persist.

Increased funding for the Opioid Overdose Prevention and Surveillance program in CDC's National Center for Injury Prevention and Control would: expand prescription drug monitoring programs and surveillance; strengthen evidence-based prevention efforts that address lax prescribing practices and adverse life experiences that lead to self-medication; and strengthen CDC's surveillance systems to translate data into action by educating consumers and equipping health departments with resources. As Congress continues to invest in addressing the epidemic, we urge you to prioritize primary prevention of substance misuse. TFAH-recommended fiscal year 2020 funding levels:

—Opioid Overdose Prevention and Surveillance—$650,000,000

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[3] The State of Obesity: Better Policies for a Healthier America, Washington, DC: Trust for America's Health and the Robert Wood Johnson Foundation, 2018.

[4] The Impact of Chronic Underfunding on America's Public Health System: Trends, Risks, and Recommendations, Washington, DC: Trust for America's Health, 2019.

[5] Promoting Health and Cost Control in States: How States Can Improve Community Health & Well-Being Through Policy Change, Washington, DC: Trust for America's Health, 2019.

[6] Pain in the Nation: The Drug, Alcohol and Suicide Crises and the Need for a National Resilience Strategy, Washington, DC: Trust for America's Health and Well Being Trust, 2017.

PUBLIC HEALTH INFRASTRUCTURE

TFAH urges the Committee to include funding for public health infrastructure, including funding public health data capabilities. The House fiscal year 2020 bill includes a $100 million down payment on modernization of CDC and public health department information technology, data and data systems, and the Senate bill should match this funding level. A similar proposal was included in the discussion draft of the Lower Health Care Costs Act, released by Senators Lamar Alexander and Patty Murray. Data is critical to the operations of public health, but many health departments rely on archaic systems—phone, fax, and paper—to communicate time sensitive information on diseases and outbreaks. These outdated systems result in costly delays in detecting and responding to outbreaks. TFAH-recommended fiscal year 2020 funding levels:

—Public Health Data Systems Modernization—$100 million

In addition, we urge the Committee to fund core public health infrastructure as part of any infrastructure package advanced by Congress. The public health system faces unprecedented 21st century challenges, ranging from the opioid crisis to extreme weather to emerging infectious diseases, and is doing so with, in many cases, 20th century infrastructure—outdated laboratories and technologies, aging facilities and lack of workforce. Only about half of the U.S. population is served by a comprehensive public health delivery system, and in some States, that number is closer to zero.[7] An investment in core, cross-cutting public health infrastructure would build a modern, nimble public health system capable of responding to emerging threats. TFAH-recommended fiscal year 2020 funding levels:

—Core Public Health Infrastructure—$300 million

CONCLUSION

TFAH appreciates the opportunity to present this testimony to the Committee and we hope that you will continue prioritizing public health in fiscal year 2020. Sustained, continuous funding for public health and prevention is vital to the health and well-being of Americans and will continue the enormous strides in improving population health this country has already realized. By restoring previous budget cuts and expanding prevention activities, we will reinforce our ability to protect and improve the lives of communities nationwide. Thank you.

PREPARED STATEMENT OF THE TUBERCULOSIS ROUNDTABLE

On behalf of the Tuberculosis (TB) Roundtable coalition, we are pleased to submit this testimony to the Senate Committee on Appropriations, Subcommittee on Labor, Health and Human Services, and Education (LHHS) for consideration in fiscal year 2020 appropriations. The TB Roundtable is comprised of organizations focused on Federal advocacy for the domestic and global elimination of TB. Specifically, we seek to make the subcommittee aware of the valuable public health role of the Centers for Disease Control's (CDC) domestic TB elimination program (DTBE) within the National Center for HIV, Viral Hepatitis, STI, and Tuberculosis Prevention (NCHHSTP), which is currently funded at $142.2 million in fiscal year 2019. We urge the Subcommittee to match or exceed the House LHHS funding recommendation for a $10 million increase to DTBE, a total of $152.2 million in fiscal year 2020. CDC's mandate is to protect Americans from public health threats at home and abroad. Yet its work on global TB is underfunded and is mostly transferred in through other accounts. In addition, we urge the Subcommittee to commit to reaching the House LHHS increase for $10 million to the CDC's Division of Global HIV and TB (DGHT). We request that this funding be provided not through the CDC's domestic TB elimination program, or out of that Division's funding, but rather through a new budget line for CDC's work in global health.

These increased resources for DTBE are necessary to restore State TB program capacity, lost through years of flat funding and reductions in public health staffing, implement the U.S. National Action Plan to Combat Multi-Drug Resistant (MDR) TB, implement a national TB prevention program, address ongoing issues in the supply of TB therapeutics and products, and expand urgently needed research and development (R&D) for TB. Increases to DGHT will allow the agency use its unique technical expertise to directly address the nexus between the global TB epidemic and the TB epidemic in the U.S. TB. A direct funding stream and increase would help strengthen TB elimination programs in highly burdened countries, focusing on

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[7] National Longitudinal Survey of Public Health Systems. In Systems for Action, 2018. http://systemsforaction.org/national-longitudinal-survey-public-health-systems.

countries contributing to the TB burden in the U.S. such as Mexico, Vietnam and the Philippines.

TB is an airborne disease, causing more deaths than any other single infectious disease agent globally. Over 10.0 million people worldwide fell ill with TB, resulting in 1.6 million deaths in 2017 alone.[1] In 2018, 9,029 people in the United States had TB but 22 States reported TB case increases.[2] The CDC cautions that these data demonstrate that the incidence of TB is declining at a slower pace, dropping from a 4.7 percent annual decline from 2010 to 2014 to 1.3 percent from 2017 to 2018, signaling that we have reached the limit of what can be accomplished for TB elimination with our existing tools.[3] Four states—California, Florida, New York and Texas—continue to account for about half of the reported cases of TB in 2018.[4]

Drug-resistant TB (DR–TB), identified by CDC as a serious antibiotic resistant threat, poses a challenge domestically. Between 2005 and 2015, there were 1,195 cases of MDR–TB and 31 cases of extensively drug-resistant TB (XDR–TB) reported in the U.S. This illustrates that the goal of eliminating TB in the U.S. is unlikely to be achieved in the 21st century without an infusion of needed resources to scale-up prevention focusing on those at highest-risk for active TB disease, and advancing new public health tools to address DR–TB.

DTBE is our frontline defense against this deadly disease and its mission is to promote health by carrying out public health activities in preventing, controlling, and eventually eliminating TB in the U.S. Funding provided to DTBE supports State and local TB programs, which carry out public health activities to eliminate TB across the U.S. Furthermore, the domestic TB program also conducts programmatically-relevant research through its TB Trials Consortium (TBTC), to inform public health practices and create tools used by programs.

TB was once the leading cause of death in the U.S., but significant boosting of funding and reorganization of CDC's domestic TB program aligned resources and research to address escalating outbreaks of DR–TB occurring among vulnerable communities in the 1980's. In part to increases in funding, DTBE has been tremendously successful in lowering rates with strengthened control and prevention strategies over time. This is a public health success story, and illustration of the critical importance of adequate and appropriate funding to strengthen and sustain public health work.

However, the domestic TB program has essentially received flat funding since fiscal year 2012, which has resulted in stagnant numbers of TB cases and rates in the past 3 years, a slowing annual decline of incidence, and the rise of deadlier drug-resistant forms of TB. When accounting for inflation using the Biomedical Research and Development Price Index (BRDI)—which calculates how much the cost of conducting research and public health activities must change each year to maintain purchasing power—between fiscal year 1994 and fiscal year 2016, CDC's domestic TB program budget in constant dollars according to BRDI declined by more than 49 percent.[5] This gap only continues to grow if funding increases goes neglected, making it difficult for TB programs to be prepared for this evolving infectious threat. Further erosion of funding will only result in erosion of our successes led by our State and local programs, and new funding increases are needed to sustain programs to overcome the challenge of eliminating TB in the U.S.

Further compounding budgetary challenges and stagnation of resources, have been infrastructural issues related to aging public health tools in the form of inadequate treatments, diagnostics and vaccines that are available to combat TB, and disruptions in supply of current tools. Current DR–TB treatment regimens can involve 250 injections and 15,000 pills over at least a two-year period, and side effects often ranging to permanent hearing loss, nerve damage, depression, kidney complications, and other issues. Additionally, a history of acute TB drug shortages in the U.S. due to unstable market conditions have had severe public health consequences, limiting efforts to address outbreaks and challenging efforts to cure those diagnosed with TB. The drugs are often prone to shortages and in the event of interruptions in our Nation's TB drug supply, persons with TB disease may lapse and TB can spread. Treatment interruptions, or incomplete regimens, can foster drug-resistance. Additionally, treatment costs for patients with TB disease increases as

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[1] World Health Organization. Global Health Observatory Data—tuberculosis. https://www.who.int/gho/tb/en/.

[2] Talwar A, Tsang CA, Price SF, et al. Tuberculosis—United States, 2018. MMWR Morb Mortal Wkly Rep 2019;68:257–262. DOI: http://dx.doi.org/10.15585/mmwr.mm6811a2.

[3] Ibid.

[4] Ibid.

[5] Treatment Action Group. Securing a Tuberculosis-Free Future through the Visionary Research of the CDC's Tuberculosis Trials Consortium. January 2018, http://www.treatmentactiongroup.org/sites/default/files/crag__tbtc__brief__1__10__18.pdf.

drug resistance escalates. While the rate of TB cases may seem low, direct treatment costs in the U.S. average $19,000 to treat a single case of drug-susceptible TB (DS–TB), $164,000 for MDR–TB and upwards of $526,000 to treat XDR–TB. Much of these resources come at the expense of already strained TB program budgets.[6]

A modest and strategic investment in fiscal year 2020 to strengthen the CDC's domestic TB elimination program's ability to carry out its core functions will put our Nation on the path to achieving true TB elimination, cost-effectively. An estimated 13 million people in the U.S. have latent TB infection. Investing in TB prevention saves money long-term by preventing future costlier cases of active TB. In one analysis, during 1992–2014, 368,184 incident TB cases were reported, and cases decreased by two thirds during that period through the strategic implementation of various TB prevention measures.[7] Modeling during this time indicates that the societal benefits of averted TB cases ranged from $3.1 to $14.5 billion.[8] Another analysis finds a $43 return on investment for every dollar spent on reducing TB.[9] With a nominal increase to the domestic TB program to scale-up targeted prevention efforts among the 13 million with TB infection, future cases of active cases can be successfully averted with significant savings to the public health system. Furthermore, a groundbreaking TB preventative therapy, called 3HP, has drastically cut down treatment from 9 months of daily treatment to 3 months of once-weekly treatment was developed through TBTC. Scaling-up this homegrown treatment innovation through TB programs in a nationwide prevention effort ensures the practical implementation of effective taxpayer-funded technologies like 3HP among those who are most vulnerable to TB, expands access to the benefits of this science, and get us even closer to full elimination.

Additional resources for the domestic TB elimination program can also help address issues of drug supply—an ongoing national problem—and contribute to solving the unique challenges of a fragmented market for TB products. Among the solutions considered could be emulating the successful Global Drug Facility (GDF) an efficient centralized/pooled procurement model that was built through U.S. taxpayer support that could be implemented stateside to stabilize the market and mitigate shortfalls in the domestic supply for TB products. With a relatively nominal investment in fiscal year 2020, the HHS Supply Service Center at Perry Point, Maryland, which currently administers a small stockpile of TB drugs and serves domestic TB programs by filling gaps in the supply could be further strengthened and inventory expanded to meet demand by programs for these important, yet vulnerable, public health products.

Lastly, the research and development (R&D) role of the TBTC within DTBE cannot go understated. TBTC research has generated dramatic global health advancements, for example in the shortening of treatment, which have led to the changing treatment guidelines from the WHO to national programs in countries where TB is most endemic. In fiscal year 2020, the TBTC researchers will engage in a re-competition process to devise an agenda for the next wave of programmatically-relevant research to eliminate TB. This is an opportunity to ensure the next 5 years advance emerging and innovative research we need in the form of new tools. Recognizing the importance of R&D at the UN High-Level Meeting on TB in 2018, national governments around the world are now committed to mobilizing resources to meet a globally accepted fair-share target of contributing 0.1 percent of gross expenditure in R&D towards TB to overcome a $1.3 billion annual funding gap.[10] The U.S. government is the world's leading funder of TB R&D at $313.5 million, of which $18.3 million is contributed by CDC, making the agency the tenth largest TB R&D funder globally.[11] However, to capitalize on TBTC's expected re-competition to strengthen the research agenda and for the U.S. to reach its own 0.1 percent funding target, an additional $131 million split among several agencies such as CDC is needed.[12] Doing so will allow the U.S. to continue to lead on the research and implementation

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[6] U.S. Centers for Disease Control and Prevention. The Costly Burden of Drug-Resistant TB in the U.S. https://www.cdc.gov/nchhstp/newsroom/docs/factsheets/costly-burden-dr-tb-508.pdf.

[7] Castro KG, Marks SM, Chen MP, et al. Estimating tuberculosis cases and their economic costs averted in the United States over the past two decades. Int J Tuberc Lung Dis. 2016;20(7):926–933. doi:10.5588/ijtld.15.1001.

[8] Ibid.

[9] The Economist. The economics of optimism. January 2015 https://www.economist.com/finance-and-economics/2015/01/22/the-economics-of-optimism.

[10] Treatment Action Group. Investing in R&D to End TB: A Global Priority. November 2017, http://treatmentactiongroup.org/sites/default/files/Funding%20target%20brief__final__31Oct.pdf.

[11] Treatment Action Group. Tuberculosis Research Funding Trends 2005–2017. December 2018. http://www.treatmentactiongroup.org/sites/default/files/tb__funding__2018__final.pdf.

[12] Treatment Action Group. Closing the Gap in Tuberculosis Research Funding: Actions for U.S. Congress. February 2019, http://www.treatmentactiongroup.org/sites/default/files/

of new tools for TB by leveraging its research expertise at CDC to coordinate with other federally-funded research institutions under LHHS, including NIAID and BARDA. Continuing to support TB R&D at CDC and other agencies within the U.S. government can catalyze other national governments to make similar commitments.

In summary, we thank the subcommittee for its continued support for the domestic TB program at CDC. We fully acknowledge that the Subcommittee has a difficult task in strategically appropriating funding within numerous agencies and programs under LHHS with this year's upcoming budget process. However, we urge you to leverage the programs and research that the domestic TB elimination program has pioneered by matching or exceeding the House's funding level at $152.2 million in fiscal year 2020, and we urge the Subcommittee to support a $10 million increase CDC's DGHT as recommended by the House to allow the agency to use its unique technical expertise to directly address the nexus between the global TB epidemic and the TB epidemic in the U.S. These funding levels will put the U.S. back on the path to eliminating TB.

PREPARED STATEMENT OF THE U.S. HEREDITARY ANGIOEDEMA ASSOCIATION

SUMMARY OF FISCAL YEAR 2020 RECOMMENDATIONS

—Provide the National Institutes of Health (NIH) with a $2.5 billion increase in discretionary funding for fiscal year 2020 to bring overall agency funding up to a minimum of $41.6 billion annually.

—Continue to encourage advancement and expansion of the hereditary angioedema (HAE) research portfolio at NIH, as well as research efforts focused on rare conditions more broadly, through timely committee recommendations.

—Please provide proportional funding increases for NIH's various Institutes and Centers leading HAE research efforts, most notably; the National Institute of Allergy and Infectious Diseases (NIAID), the National Centers for Advancing Translational Sciences (NCATS), and the National Heart, Lung, and Blood Institute (NHLBI).

—Provide the Centers for Disease Control and Prevention (CDC) with at least a $500 million increase in discretionary funding for fiscal year 2020 to bring overall agency funding up to a minimum of $7.8 billion annually.

—Encourage the Centers for Medicare and Medicaid Services (CMS) to prevent discrimination in health coverage by ensuring rare disease patients do not face arbitrary restrictions when seeking charitable assistance to maintain access to life-sustaining care and therapy, and to prevent from being steered into Federal need-based and illness-based programs that they would not otherwise qualify for while properly managing their illness.

Chairman Blunt Ranking Member Murray, and distinguished members of the Subcommittee, thank you for the opportunity to present the views of the U.S. Hereditary Angioedema Association (U.S. HAEA) on funding and related policy items for NIH, CDC, and CMS during consideration of appropriations for fiscal year 2020. First and foremost, thank you for supporting these programs in fiscal year 2019. It is our hope that this invest will continue for fiscal year 2020 to ensure that meaningful progress can continue in specific, promising areas.

U.S. HAEA is a patient-driven organization comprised of affected individuals and their families. In this regard, we would primarily like to recognize this Subcommittee for its leadership and commitment to providing medical research and public health programs with notable funding increases for fiscal year 2018. This investment will have a tangible positive impact for patients by significantly improving scientific inquiry and public health activities.

U.S. HAEA is a non-profit patient advocacy organization dedicated to serving the estimated 6,000 HAE sufferers in the U.S. We provide a support network and a wide range of personalized services for patients and their families. We are also committed to advancing clinical research designed to improve the lives of HAE patients and ultimately find a cure.

HAE is a painful, disfiguring, debilitating, and potentially fatal genetic disease that occurs in about 1 in 30,000 people. Symptoms include episodes of swelling in various body parts including the hands, feet, face and airway. Patients often have bouts of excruciating abdominal pain, nausea and vomiting that is caused by swelling in the intestinal wall. The majority of HAE patients experience their first attack during childhood or adolescence. Approximately one-third of undiagnosed HAE patients are subject to unnecessary exploratory abdominal surgery. About 50 percent of patients with HAE will experience laryngeal edema at some point in their life. This swelling is exceedingly dangerous because it can lead to death by asphyxiation. The historical mortality rate due to laryngeal swelling is 30 percent.

A RESEARCH SUCCESS STORY

There was a time not long ago that HAE was a debilitating, and often life-ending, chronic disease. In addition to the serious health impacts, affected individuals suffered with trauma, anxiety, and PTSD stemming from torturous attacks (and the uncertainty of when the next attack might occur). Due to advancements in medical research, HAE patients now have access to life-altering and life-sustaining medications. Properly medically managing the disease now allows many the freedom to work productively, live independently, and thrive.

While we are appreciative of the scientific progress, much more can be done. There is no cure of HAE and treatment is highly individualized. Little is known about the underlying mechanisms of disease and successful treatment often involves personalized care and a customized treatment regimen prepared by a leading physician expert (and trial and error).

NIH has a modest, but meaningful HAE research portfolio. Recent annual investments will facilitate growth in this portfolio and have led to important new scientific projects. The ongoing research at NIH (and complimentary research through the Department of Defense Peer-Reviewed Medical Research Program) will lead to a time when HAE patients can move beyond their disease. However, a key question that remains is how much of this investment is going to rare and ultra-rare disease research programs, particularly in-light of the “big ticket” items that are often now the focus of annual research appropriations.

THE IMPORTANCE OF PROPER HEALTH COVERAGE AND ACCESS

The HAE community first became aware of the fact that the Centers for Medicare and Medicaid Services (CMS) had allowed private insurers offering marketplace plans to deny coverage to individuals receiving charitable assistance in 2015 when about a dozen HAE patients in Louisiana received notices that their coverage was being cancelled due to the fact someone else had helped them pay their bills. Since that time, the practice has become pervasive and HAE patients are regularly informed that they will lose coverage if they receive any charitable assistance, that they may be committing fraud, and that they may face legal action if they accept assistance. This dynamic has effectively become a back door to pre-existing condition discrimination that is implemented to steer HAE patients into tax-payer funded healthcare. Moreover, the practice now stretches behind just marketplace plans due to the inability to address this issue when it first began jeopardizing health for patients with no alternatives.

Many HAE patients properly manage their illness when they have proper access to healthcare and treatment. HAE patients would typically not qualify for need-based or health-based government programs due to the life-sustaining nature of their treatment. If proper coverage is lost though, an HAE patient may have to endure a life-threatening experience of waiting without preventative treatment while they spend down to qualify for Medicaid or become sick enough to apply for disability (beyond relying on emergency care once a potentially life-ending attack occurs).

U.S. HAEA has joined with other patient-driven organizations experiencing the harm of current pre-existing condition discrimination facilitated by barriers to charitable assistance and the related practice of a restrictive co-pay accumulator to form the ad hoc group, United for Charitable Assistance (UCA). While UCA will submit its own testimony on behalf of the community under separate heading, we join with all stakeholders in asking this subcommittee to once again highlight these rare-disease challenges for CMS and request the current barriers are resolved to protect patients that have no other reasonable options to maintain coverage.

Thank you for your time and for your consideration of these requests.

[This statement was submitted by Anthony Castaldo, President, U.S. Hereditary Angioedema Association.]

Prepared Statement of the United for Charitable Assistance

SUMMARY OF FISCAL YEAR 2020 APPROPRIATIONS RECOMMENDATIONS

—Please continue to support and advance committee recommendations, as well as related funding and policy initiatives, which further encourage HHS and the Centers for Medicare and Medicaid Services (CMS) to address arbitrary barriers that disrupt patient access to essential charitable assistance in a meaningful and timely way.

—Please work with your colleagues to encourage HHS to establish a transparent and patient-centered regulatory system formally governing charitable assistance programs that is consistent with the current framework of OIG opinions and ensures all policymakers and stakeholders have appropriate mechanism to address challenges and opportunities in this space.

—Please continue to support investment in medical research through the National Institutes of Health and public health through the Centers for Disease Control and Prevention to further improve care and health outcomes for patients facing complex illnesses.

Chairman Blunt, Ranking Member Murray, and distinguished member of the Subcommittee, thank you for your leadership on health funding and patient care issues. On behalf of United for Charitable Assistance (UCA), we deeply appreciate the opportunity to provide a critical, patient-centered perspective as you consider fiscal year 2020 appropriations issues that impact healthcare coverage and patient access. Most notably, we urge you to continue to advance committee recommendations that feature and emphasize the need to quickly restore access to critical charitable assistance programs that serve patients with no other options (in a manner consistent with fiscal year 2016 and fiscal year 2017). Thank you again for this important opportunity. Please consider UCA a resource on this issue moving forward.

ABOUT UNITED FOR CHARITABLE ASSISTANCE

We are an ad hoc group of patient community leaders that seek to protect access to the charitable financial support programs, which serve as a crucial part of the healthcare safety net for individuals with rare, chronic, and life-threatening medical conditions. We work together to educate policymakers so they understand the value, impact, and vital nature of these programs and ultimately support efforts to actively defend the lives and livelihoods of those facing serious conditions that can now be better-managed through proper care and innovative therapies.

ABOUT CHARITABLE ASSISTANCE

Over recent years, CMS promulgated rules that effectively allow private insurance companies to simply deny (or reserve the right to deny at will) any premium or related healthcare payments made on behalf of a patient. While these restrictions initially started in marketplace plans, they have spread to Medigap plans, and various other forms of coverage. The tangible result of these policies is that patients are often denied access to mission-driven charitable support from non-profits, civic groups, and houses of worship. Ultimately, these restrictions form a back-door to pre-existing condition discrimination where they are targeted at the most vulnerable populations and patients lose their coverage due to an inability to utilize available support or are simply steered towards one of the few remaining plans that has not implemented restrictions (if they are available in their State). Most recently, the practice of copay accumulators has taken hold where some assistance is accepted, but it is never applied to the patient's out-of-pocket limits, thus rendering the support inconsequential for the seriously ill.

The situation is particularly dire for patients with rare, chronic, and life-threatening illness that rely on innovative life-sustaining medications and who occasionally turn to charities following a job loss or similar hardship to ensure there is no catastrophic disruption in access to care. Often times, when properly medicated, these patients work and contribute to society, and they do not qualify for Medicaid or similar need-based programs. Further, despite the severity of their illness, the therapy or medical intervention likely blunts or slows the progression of their disease meaning they also do not readily qualify for disability programs. When assistance and access to proper care is lost, a dangerous situation is created where the dramatic decline in health rapidly outpaces the patient's ability to transition on to tax-payer funded safety net programs.

We cannot overlook the fact that many patients in the aforementioned situation also continue to turn to charitable assistance during the process of transitioning on to Federal programs as their illness progresses. The disability waiting periods alone would be insurmountable for many without charitable assistance. In this regard, the need for charitable assistance is certainly not mitigated in Medicare and related programs with some patients utilizing charitable assistance to make ends meet and cover cost-sharing requirements.

From our experience, there appears to be dangerous misconceptions that alternatives to charitable assistance exist, that manufacturers can bridge gaps by voluntarily offering free product as needed, and that Medicare Part A and hospital emergency rooms can provide a base solution for those in extreme circumstances. The reality is that no alternatives exist, there is no comparable or cost-effective substitute for properly managing an illness, and charitable assistance programs will need to be an integral part of the healthcare safety net for the foreseeable future.

When charitable assistance was started decades ago, it was a benevolent response to real and immediate needs facing the seriously ill. This assistance was intended to protect those with pre-existing conditions, prevent medical bankruptcy, and stop involuntary divorce. These were the same goals shared by the core patient protections advanced by the Affordable Care Act and supported on a bipartisan basis in Congress. These patient protections have been an improvement, but they have not supplanted the need for charitable assistance programs.

CONTEMPORARY EXAMPLES OF CHARITABLE ASSISTANCE CHALLENGES (PATIENT STORIES)

Collen.—Colleen is a working mother with two young children from Connecticut. Her family has health insurance through her husband's employer. Colleen's family has, relied on a combination of a manufacture co-pay coupon and non-profit assistance to make ends meet. Now, the non-profit they relied on no longer offers support, leaving them with a financial shortfall. To make things worse, their health insurance plan now refuses to apply their co-pay assistance to their deductible and out-of-pocket maximum.

Colleen says, "It is double dipping on the part of the insurance giants, and it is unconscionable. These co-pay cards are meant to take the pressure off very sick, very expensive patients. And instead we're getting hit just as hard, even when we have a co-pay card. We are seriously considering pulling my daughter from her preschool for next year because we just can't absorb all these extra healthcare costs."

Edith.—Edith is in her 70s and a Medicare recipient from Florida who was diagnosed with a rare, chronic, and life-threatening illness about 5 years ago. She takes two targeted therapies to manage her condition. Recently, the non-profit charity she had relied on stopped offering co-pay assistance.

Edith says, "after [I stopped getting copay assistance], every number that I tried either didn't help with my condition or was out of funds. It was scary there for a while because I don't have that kind of money to be able to pay that every month. If I didn't have the medication I wouldn't be around. I would have passed away." Edith's husband adds, "without her medications she cannot breathe. Without these drugs I would lose my wife in a day."

Irene.—Irene is in her 60s and a former building supervisor from Virginia. She now receives Medicare due to disability. Irene's cost sharing requirements outpace her fixed income.

The non-profit organization that had been assisting Irene with her co-pay recently stopped offering funds. Irene said, "I was a single mom and over the years worked very hard to support myself and my son, but there was never enough to save or put away. My [financial assistance] grant runs out... in 21 days. I don't have a clue as to what to do...Basically, I have exhausted all means of other resources and am mentally preparing myself to die."

PREPARED STATEMENT OF THE UNITED STATES WORKFORCE ASSOCIATIONS

Dear Chairman Blunt and Ranking Member Murray:

The undersigned organizations make up the United States Workforce Association (USWA), a collaborative effort of local workforce boards, businesses, educational institutions, and organizations involved in workforce and economic development activities across the country. These organizations are directly involved in the implementation of the bipartisan Workforce Innovation and Opportunity Act (WIOA) of 2014, specifically promoting the successful execution by local workforce boards of the law to serve businesses, employers, and job—and career-seekers. With national unemployment levels near all-time lows, the available labor market faces significant barriers to employment—lack of high school or post-secondary credential, ex-offender, long-term unemployed, housing, transportation, child care—and the list could continue. The employer-led workforce system, which is structured using the Workforce Innovation and Opportunity Act (WIOA), is poised to address these community needs but has not been funded to its authorized levels since it was passed by Congress in 2014.

As the Senate Appropriations Committee considers the fiscal year 2020 Labor-HHS Appropriations Bill, we urge you to support further Federal investment into WIOA and fully fund the law to its authorized levels. Appropriated levels have fallen short of authorized levels specifically in Title I accounts at the Department of Labor (Adult Employment and Training Services, Youth Workforce Investment Activities, and Dislocated Worker Employment and Training Services). An expanded Federal investment across WIOA programs leads to more job training, education, skills development and innovative, proven practices like industry-based sector partnerships, career pathways, and apprenticeships. Local workforce development boards are currently executing on these strategies working directly with employers to address their talent needs.

With sustained economic prosperity for America as a priority, this increased Federal investment could not come at a more opportune time. The skills gap is real and workforce boards are on the front lines with various stakeholders including employers, community colleges, post-secondary institutions, high schools, non-profits and career and technical education programs, to address the problem.

Without a spending cap/budget deal in place, these programs are at serious risk for harmful sequestration cuts when we can least afford them as a Nation. The fiscal year 2020 Labor, Health and Human Services, Education, and Related Agencies Appropriations bill must fully fund all Titles I, II, III, and IV at the level authorized by the Workforce Innovation and Opportunity Act (WIOA).

The funding levels we are requesting in the fiscal year 2020 Labor, HHS, Education Appropriations Bill are listed below:

Title I—Department of Labor

—$899.987 million for Adult Employment and Training Services,
—$963.837 million for Youth Workforce Investment Activities, and
—$1.436 billion for Dislocated Worker Employment and Training Services

Title II—Department of Education

—$678.640 million for Adult Education

Title III—Department of Labor

—$663,052,000 for Wagner-Peyser (Fiscal Year 2019 Enacted)

Title IV—Department of Education

—$3,521,990,000 for Vocational Rehabilitation Services (Fiscal Year 2019 Enacted)

FISCAL YEAR 2020 ADMINISTRATION BUDGET PROPOSAL LANGUAGE

We also wanted to highlight concerning language contained in the fiscal year 2020 Department of Labor Budget Proposal that would give Governors more authority to re-designate and consolidate local workforce boards. The budget proposal language would waive protections given to local control by circumventing Section 106 of the Workforce Innovation and Opportunity Act (WIOA). Congress recognized that local economic conditions are best addressed at the local level when WIOA was passed in 2014. That local control is critical when dealing with employers and other stakeholders as we can address economic issues with flexible resources and innovative solutions. We oppose the language included in the budget and encourage you to further support local control within the Federal workforce system.

This training, support and business partnership is vital to our country's economic prosperity.

Sincerely.

Bob Lanter
Executive Director
California Workforce Association

Kelly Folks
Kelly Folks, President
Rocky Mountain Workforce Development Association

Julie Courtney
Julie Courtney, Director
McHenry County Workforce Network
(Illinois)

Tonja Mettlach, Executive Director
Massachusetts Workforce Association

Luann Dunsford
Luann Dunsford, CEO
Michigan Works! Association

Melinda Mulawka Mack
Executive Director
New York Association of Training and Employment Professionals

Jeff Frederick
President
North Carolina Association of Workforce Development Boards

John Trott
President
Ohio Workforce Association

Greg Vaughn
Executive Director
Texas Association of Workforce Boards

Mari Kay-Nabozny
Mari Kay-Nabozny
Chief Executive Officer
Northwest Wisconsin Workforce Investment Board, Inc.

Michelle Day, President
Maryland Workforce Association

Linda Nguyen, President
Washington Workforce Association

Bridget Dazey
Bridget Dazey, Chair
Oregon Workforce Partnership

Kimberly L. Bodine
Kimberly L. Bodine, President
Florida Workforce Development Association

Teri Drew CHAIRMAN
Teri Drew, Chairman
Arizona Workforce Association

Ricki Kozumplik
IN Workforce Board Association

PREPARED STATEMENT OF THE UNITED TRIBES TECHNICAL COLLEGE

United Tribes Technical College (UTTC) is celetrating fifty years of educational service, twenty-five years as a 1994 Land Grant Institution, and thirty-seven years of accreditation by the Higher Learning Commission. The ongoing mission and vision are to train American Indian students with vocations that will provide them with the skills they need to take care of themselves and their families while they contribute to their nations and society. The legacy of workforce development and employment training continues through the offering of certificates and associate and bachelor degrees. Eighty-nine percent of our students are enrolled in certificate and associate degree programs of study.

Our students are, by and large, from low-income families and come from many tribal nations (48 in 2017). We are governed by the five tribes located wholly or in part in North Dakota. UTTC is not part of the North Dakota University System and does not have a tax base; however, we do receive limited State-appropriated funds for non-Native students. The fiscal year 2020 funding requests of UTTC for the Department of Education 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 $436,000 above the fiscal year 2019 enacted level and $1.7 million above the Administration's request. 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.
- —$65 million in discretionary funds as requested by the American Indian Higher Education Consortium for Title III–A of the Higher Education Act (Strengthening Institutions program). Normally, the Title III–A request would be about

half that amount but the Title III–A Part F mandatory funding has expired and unless the funds are reinstated the shortfall needs to be made up with discretionary funding. The total fiscal year 2019 amount for Title III–A Parts A and F was $61.8 million.

—Sufficient funding for the Pell Grant program to provide the maximum grant. We support the Administration's request to provide the maximum Pell Grant award of $6,195 and to expand eligibility to students enrolled in high-quality short-term programs that lead to a credential, certification, or license in a high-demand field. Eighty 4 percent of our degree-seeking students received Pell Grants for the 2017–2018 academic year.

Tribally Controlled Career and Technical Institutions

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. Our most popular certificate programs are the sixteen-week Heavy Equipment Operator Program and the nine-month Welding Technology Program. UTTC is now the only welding test site in the State of North Dakota approved by the American Welding Society, and while the North Dakota Bakken oil boom has diminished, these professions remain in demand. We are now able to train students for good paying in-demand employment with a focus on career rather than just a job.

Our Criminal Justice and Business Administration programs are set up as a 2 + 2 program with the associate degreees setting the foundation for a bachelor's degree. We are well situated to provide basic and supplemental law enforcement training for the Great Plains tribes and urge your support with the Department of Interior/Bureau of Indian Affairs to work with us and tribes on the establishment of a Northern Plains Indian Law Enforcement Academy at UTTC.

Funding for United Tribes Technical College is a good investment. We have:

—An unduplicated count of 525 students in 2017–18. There were 494 undergraduate degree-seeking students, 4 non-degree seeking students, and 27 dual credit high school students enrolled. There were 1,531 continuing education students for a total student count of 2,056 for 2017–18.

—Our students are very low income. Approximately 84 percent (407) of the 494 degree seeking undergraduate students at UTTC received Pell grants for the 2017–18 academic year.

—From 2017—2018, UTTC had a fall to fall retention rate of 51.4 percent and a 2017 fall to spring semester persistence rate of 74.7 percent.

—Using the North Dakota state longitudinal data system, which tracks graduates who gain employment within North Dakota, 56 of the 87 graduates were employed in North Dakota for a placement rate of 64 percent. (Note, this number does not include those who may have been employed outside of North Dakota.)

—The fall graduates from December 2017 who were employed in North Dakota earned an average of $7,414 in the third quarter after they graduated, which averages about $29,656 annually. In addition, 38 of the students who graduated continued their education.

—A projected return on Federal investment of 20–1 (2005 study).

—Higher Learning Commission Accreditation through 2021. A 2017 campus site visit indicated we have a firm foundation for furthering efforts as a data driven institution.

—Campus services include: 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 critical role in the regional economy. A North Dakota State University study reports that the five tribal colleges in ND made a direct and secondary economic contribution to the state of $192,911,000 in 2016 and UTTC had a $59.6 million direct and secondary economic impact on the Bismarck/Mandan communities for the same period.

Title III–A (Section 316) Strengthening Institutions

The Title III–A Strengthening Institutions funding is very important for all the tribal colleges and we support the American Indian Higher Education Consortium's request of $65 million for discretionary funding if the $30 million mandatory (Part F) funding is not restored. While these are not operational funds, they are critical for developmental activities and provide an opportunity for a modest amount of construction funding. 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. Of the students who reside on campus, approximately twenty-five percent are housed in the 100-year-old buildings of what was previously Fort Abraham Lincoln and the other 75 percent of students reside in homes donated by the Federal Government in 1973. These buildings require major rehabilitation.

Title III funds provide much needed support to strengthen academic offerings and infrastructure. Specifically, Title III has been instrumental in the College's efforts to provide Baccalaureate programs, online Associate programs, and increase the technology infrastructure necessary to support student learning and campus management functions. Professional development activities have been supported by Title III resulting in enhanced intellectual and technical capacity of faculty and staff.

Additional activities carried out with support of Title III funding have been associated with increasing the College's Institutional Resources capabilities in order to strengthen relationships with alumni and forming relationships with organizations and individuals who may become supporters of the College. With the current Title III award, the College is anticipating expanding academic offerings through the development of a Master's level program. The support of Title III will be critical for attaining accreditation approval, program development, and acquiring highly qualified faculty.

Some members of your Subocmittee have made a point to visit places in Indian Country and we would love to be able to arrange for you to visit United Tribes Technical College. Thank you for your consideration of our requests. Hecetu yedo. (It is so).

[This statement was submitted by Leander R.McDonald, PhD, President, United Tribes Technical College.]

PREPARED STATEMENT OF DONNA WALBERG AND LEE WALBERG

Dear Chairman Blunt:

My husband who has Alzheimer's disease and I support a $6,000,000 increase in funding of for the Administration of Community Living's Alzheimer's Disease Programs Initiative (ADPI) for a total of $29,500,000. This program supports and promotes the development and expansion of dementia-capable home and community-based long-term services and support systems in States and communities. In the State of Minnesota, for nearly 20 years, ADPI grants have funded initiatives that have built infrastructure to serve families in both rural and urban communities, created culturally appropriate caregiver education, and worked with healthcare systems to become dementia capable. Minnesota has long been known as a leader in the field of dementia, with our Act on Alzheimer's Initiative we developed one of the most influential and highly regarded State Alzheimer's plans in the Nation. Minnesota has created more than 50 Dementia Friendly Communities. St. Cloud where we live is one of them.

My husband Lee, the love of my life, was diagnosed with Alzheimer's Disease in 2012. We both cried, it was a devastating diagnosis, even though he had been symptomatic for several years. He is now in the mid stage of the disease moving slowly but steadily to late stage. We are fortunate that he was diagnosed early by a physician knowledgeable about the disease. We were quickly referred to a well known neurologist and neuropsychologist who are leaders in the field. We participated in two clinical trials. Both seemed to slow the progression of the disease but as has become clear there will be no cure for people who currently have the disease. This makes maintaining and increasing the funding for the ADPI program doubly important. At 61 my husband was young when he was diagnosed, he had to leave his job years before he was ready to, I am working part-time into my retirement years to pay for the additional care my husband is beginning to need while still providing most of the care and support myself. It is challenging and exhausting.

ADPI Grants Built a Dementia Capable State

ADPI grants in Minnesota developed a comprehensive education program for professionals and para professionals in the field. Over the nearly 20 years of the grants thousands of providers have been trained in the best practices of supporting a person with dementia and their caregivers to continue to live independently as long as possible. Because of this initiative I am able to hire a care provider, Karen, who stays with my husband when I need to travel for work or just need a spa day with a friend. I did not need to train her, she already knew how to communicate with him (he's lost the ability to form words and make sentences easily), she already knew how to discover his rituals that make his day smoother and treats him with unfailing respect and patience. Minnesota has a cadre of these care providers that can be hired through a home care agency or directly as we do. As my husband progresses, Karen and her fellow providers will make it possible for me to continue to provide the care my husband needs at home, hopefully until he dies, that is our goal. Without the ADPI funded dementia capability training this would not have been possible. As knowledgeable as I am, I could not have provided the training that Karen needs to support my husband.

ADPI Grants Created Caregiver Supports that are Embedded in Existing Services

ADPI funding supported the development of caregiver supports in rural and urban communities in Minnesota. Minnesota's implementation of the evidence-based New York University Caregiver Intervention (NYUCI) received the Rosalynn Carter Institute on Caregiving Award. This program provides caregivers and their families with individual and group counseling sessions and was shown to delay nursing home placement on average 18 months in a randomized controlled trial. Through ADPI grants other evidence-based services for caregivers have been embedded as usual care in Minnesota's caregiving infrastructure including REACH Community and the Savvy Caregiver. I'm a graduate of the Savvy Caregiver program and I cannot tell you how that program saved my life. I was stressed beyond belief and grieving along with my husband all his losses. As a result of the Savvy Caregiver program, I now meditate regularly, make sure that I have time with my friends, have a more balanced work schedule and found and hired Karen to relieve me when I need it. My involvement in the NYUCI taught me how to ask our adult children to help out on a regular basis with chores, helped me to begin to hire out the chores they couldn't do and made us a family care team so I'm not alone in making all the decisions. Because they are care partners, they are richly involved in their Dad's life. While bit by bit we are losing him, we are also experiencing all the joy of the many things he can still do. This is a joy that our children, my husband and I would not have known without the NYUCI. Caregivers often die before the person with dementia because of overwhelming grief and burden. Because of ADPI funding, caregivers, their families and the person with dementia can celebrate life fully and live out each day with fresh vigor. I know my husband is progressing so slowly because of the support that I get.

ADPI Grants Helped to Build Dementia Capable Health Systems

Hundreds of physicians and advanced practice healthcare providers have received in person education and training to identify people who have possible dementia during regular healthcare visits, complete a diagnostic work-up and engage in joint care planning to ensure that the person with the disease is diagnosed early and they and their caregiver are connected to the services and supports that they need on an ongoing basis. Essentia, Health Partners, Allina and other large and small health systems in Minnesota have embedded or are beginning to embed these practices as routine care in their clinical practices and in their electronic medical records systems. The connections that they help make as well as their ongoing communication with the person with the disease, their caregivers and the community services provide a critical safety net ensuring that care and support is provided by both the healthcare system and the community as it is needed. My husband was diagnosed early because of his health systems adoption of dementia capable practices. My physician connects with me regularly to make sure that I'm keeping up with my own healthcare and getting the support I need as a caregiver.

As a country we all benefit from the synergies that are created when the healthcare system works closely with the person, their family and community services. The benefits go far beyond the accrued financial savings. My husband's neurologist says that he is their star, they have never seen anyone progress as slowly as he has. We have more precious family moments. I'm healthy and thriving, not weighted down by grief and worn out by care. Our circle of partners in care has grown wider and stronger. We are blessed.

In summary, over the past 20 years, the Federal Alzheimer's program, now known as the ADPI, has transformed the delivery of dementia care in Minnesota, particularly in rural communities and cultural communities in urban centers. Furthermore, the work created in Minnesota has influenced care across our Nation.

We encourage the Labor Health and Human Services, Education, and Related Agencies Subcommittee to robustly fund this program. Funding of $29,500,000 will ensure that families impacted by Alzheimer's and other dementias are not only supported, but connected with appropriate resources, services, and supports from within their communities. This is the primary Federal program focused on the development of home and community-based long-term care services and supports that can help families keep their loved ones in their home.

We thank you for this opportunity to speak about the impact and importance of the Alzheimer's Disease Program Initiative and hope that by sharing the impact of this program on our family and our State, we can motivate you to preserve its funding and integrity.

Sincerely.

PREPARED STATEMENT OF WORLD VISION US

Mr. Chairman, Ranking Member Murray, and members of the Subcommittee, I am submitting this testimony for your consideration on behalf of World Vision, one of the largest faith-based organizations working in humanitarian relief and development. Specifically, I ask that the Subcommittee seek to fund the Department of Labor's Bureau for International Labor Affairs (ILAB) at $91.125 million, including $58.825 million for the child labor grants program, $7.5 million for the worker rights program, and $6.04 million for program evaluation.

World Vision US has more than one million private donors in every State and Congressional district, partners with over 16,000 churches in the United States, and works with a wide variety of corporations and foundations. We are motivated by our Christian faith to serve every child in need and their family; those of any faith, or none. We partner with faith leaders throughout the world, equipping them to meet the needs of their communities.

We are part of a global World Vision Partnership, which implements programming to help children, families and communities through international relief, development, and advocacy assistance. Although private donors support the foundation of our work, the U.S. Government is an invaluable partner as we work to achieve our broad goals for children. We leverage this partnership to reach vulnerable children and families in nearly 100 countries around the world, ensuring that the precious resources of the American taxpayer are prudently used to promote and protect the well-being of children and communities abroad.

We also use this partnership with the U.S. government to leverage private funding. We've successfully used grant funded programs to spur private fundraising from both corporations and individuals and to leverage and integrate resources in a way that ensures taxpayer dollars go further. Through World Vision's work around the world, we see the impact that violence and exploitation can have on children and their families. 73 million children are in hazardous child labor which prevents them from attending school and is harmful to their physical, mental, and social development. Boys and girls around the world work in agriculture, mining, quarrying, fishing, factories, domestic work, and commercial sexual exploitation. 4.3 million children are in forced labor, including in situations of trafficking. The work of Department of Labor's Bureau of International Labor Affairs and its partners protect children from exploitation and violence, allowing them the opportunity to fulfill their full potential and contribute positively to their communities and countries. This work also supports the US Government's Action Plan for Children in Adversity (APCA), which is a whole-of-government framework for providing protective family care and an environment for children that is free from deprivation, exploitation, and danger. ILAB's anti-child and forced labor work encourages global economic growth and addresses exploitative business practices that undercut American workers and companies.

Our global economy feels the impact of violence against and exploitation of children. The economic costs of child labor amount to 2.4–6.6 percent of the world's gross national income annually. The global income lost by children out of school and instead engaged in hazardous work amounts to $176 billion annually. Child labor impacts the economies of U.S. Government trading partners and the investments the U.S. Government makes in other areas of development and trade. Child labor depresses wages and earning potential of future workers, keeping economic growth and achievement of development objectives stagnant. The cost to children, communities, and the global economy is too great for the U.S. government to step back from its leadership role in ending child labor and forced labor.

Since 1995, the Department of Labor through the Bureau for International Labor Affairs' Office of Child Labor, Forced Labor, and Trafficking has worked with partners to directly impact the lives of nearly two million children vulnerable to exploitative labor, combat forced labor, and address worker rights in countries with which the United States has trade agreements or preference programs. To address child labor, ILAB programs take a holistic approach, including community and government involvement to increase access to education for children and support livelihood opportunities for families to meet basic needs and reduce reliance on child labor. ILAB has been a leader in the global fight to end child labor. Since 2000, child labor has been reduced by half globally, in no small part due to the efforts of the U.S. through ILAB.

World Vision is one of many ILAB partners working to address hazardous child labor through education interventions, strengthening family livelihoods, increasing accountability of employers towards child labor standards, and sustainably building the capacity our local and national governments of countries which the U.S. has trading relationships with. For example, in Ethiopia, World Vision is working to address exploitative child labor by helping youth ages 14–17 develop marketable skills to secure appropriate work and serve as community leaders. The project aims to reach 12,000 Ethiopian male and female youth, both in school and out of school, and their 7,500 households. In the Philippines, World Vision, through funding from the Bureau for International Labor Affairs, implemented the ABK3 Livelihoods, Education, Advocacy, and Protection to Reduce Child labor in Sugarcane Areas (ABK3 LEAP) project from 2011 to 2015. The project reduced child labor in target communities by 86 percent while providing education opportunities and necessary resources for families to keep children out of hazardous forms of work.

In the Philippines, the perceived (or real) lack of quality education, difficulty staying caught up with class work, and economic drivers contributed to child labor and school dropout. To address these challenges World Vision worked with 12,310 students in over 250 schools to help struggling learners revive their interest and improve their participation in school through the Catch-Up program. Catch-Up complemented learning in the classroom and was notably important during the start of the sugarcane harvest season when students are more likely to work in the field after school with some eventually dropping out of school. The Catch-Up program trained peer teachers (Little Teachers) to support students who were struggling in their studies and boosted students' confidence in their skills while promoting engagement with learning material in the classroom. As a result, junior high school enrollment increased by 36 percent between 2012 and 2015. In the 2014–2015 school year, school attendance increased and the number of students dropping out decreased to nearly zero. The number of children who did not repeat a year level in school increased by 10 percent in 2015. This innovative and effective outreach to struggling students significantly contributed to the success of the project in reducing child labor and increasing school enrollment.

While we acknowledge the constraints and challenges of our current fiscal climate, ILAB's grant program supports economic growth for our trade partners and ensures our trade partners are effectively implementing labor standards. ILAB combines understanding the problem of child labor and forced labor through research with targeted, effective action to measurably reduce child labor and forced labor. Past proposals to end ILAB's programming to combat exploitative child labor would functionally end all U.S. programming to reduce international child labor and would directly impact the roughly 150,000 children annually who benefit from ILAB funding. ILAB's grant program not only benefits the children and families we serve, but creates the opportunity for American workers and companies to compete more effectively in the global economy.

As an organization that has worked with ILAB we can attest to the rigor of their programs and the critical support that their staff provide. ILAB is among the most rigorous donors that we work with, requiring a level of evaluation to ensure effectiveness that is not found in many other donors. They are setting a high standard for the effective and targeted use of U.S. taxpayer dollars. After more than twenty years addressing child labor and forced labor, ILAB's work is an asset to the U.S. government and provides leadership in international arenas. Presently, eight U.S. offices within the Department of State, USAID, and the Department of Labor fund programs that focus or include a component on ending violence against children globally. Almost 50 percent of spending in fiscal year 15 to end violence against children came from ILAB. As the subcommittee considers funding levels for fiscal year 2019, we hope you will take into consideration the impact of ILAB programs and the value they provide in building a better world for children and for American workers and companies.

The number of children in child labor is declining but progress has slowed significantly—child labor only declined by 9.7 percent from 2012–2016 compared to 22 percent during the 4 years prior. If progress continues at the current pace, 121 million children will still be engaged in child labor in 2025. It will take an extra push in the coming years not only to renew the rate at which we fight child labor, but also to reach the most vulnerable children, in the hardest to reach places. I ask that the Subcommittee seek to fund the Department of Labor's Bureau for International Labor Affairs at $91.125 million for the Bureau of International Labor Affairs, including $58.825 million for the child labor grants program, $7.5 million for the worker rights program, and $6.04 million for program evaluation.

Thank you for the opportunity to provide written testimony and for considering this request.

[This statement was submitted by Robert Zachritz, Vice President, Advocacy and Government Relations, World Vision US.]