DEPARTMENTS OF LABOR, HEALTH AND HUMAN SERVICES, EDUCATION, AND RELATED AGENCIES APPROPRIATIONS FOR 2017

HEARINGS

BEFORE A

SUBCOMMITTEE OF THE

COMMITTEE ON APPROPRIATIONS

HOUSE OF REPRESENTATIVES

ONE HUNDRED FOURTEENTH CONGRESS

SECOND SESSION

SUBCOMMITTEE ON THE DEPARTMENTS OF LABOR, HEALTH AND HUMAN SERVICES, EDUCATION, AND RELATED AGENCIES

TOM COLE, Oklahoma, *Chairman*

MICHAEL K. SIMPSON, Idaho
STEVE WOMACK, Arkansas
CHARLES J. FLEISCHMANN, Tennessee
ANDY HARRIS, Maryland
MARTHA ROBY, Alabama
CHARLES W. DENT, Pennsylvania
E. SCOTT RIGELL, Virginia

ROSA L. DELAURO, Connecticut
LUCILLE ROYBAL-ALLARD, California
BARBARA LEE, California
CHAKA FATTAH, Pennsylvania

NOTE: Under Committee Rules, Mr. Rogers, as Chairman of the Full Committee, and Mrs. Lowey, as Ranking Minority Member of the Full Committee, are authorized to sit as Members of all Subcommittees.

SUSAN ROSS, JOHN BARTRUM, JENNIFER CAMA,
JUSTIN GIBBONS, KATHRYN SALMON, and LORI BIAS,
Subcommittee Staff

PART 7

OUTSIDE WITNESS TESTIMONY

Printed for the use of the Committee on Appropriations

U.S. GOVERNMENT PUBLISHING OFFICE

21–344 WASHINGTON: 2016

AUTHENTICATED
U.S. GOVERNMENT
INFORMATION
GPO

COMMITTEE ON APPROPRIATIONS

HAROLD ROGERS, Kentucky, *Chairman*

RODNEY P. FRELINGHUYSEN, New Jersey
ROBERT B. ADERHOLT, Alabama
KAY GRANGER, Texas
MICHAEL K. SIMPSON, Idaho
JOHN ABNEY CULBERSON, Texas
ANDER CRENSHAW, Florida
JOHN R. CARTER, Texas
KEN CALVERT, California
TOM COLE, Oklahoma
MARIO DIAZ-BALART, Florida
CHARLES W. DENT, Pennsylvania
TOM GRAVES, Georgia
KEVIN YODER, Kansas
STEVE WOMACK, Arkansas
JEFF FORTENBERRY, Nebraska
THOMAS J. ROONEY, Florida
CHARLES J. FLEISCHMANN, Tennessee
JAIME HERRERA BEUTLER, Washington
DAVID P. JOYCE, Ohio
DAVID G. VALADAO, California
ANDY HARRIS, Maryland
MARTHA ROBY, Alabama
MARK E. AMODEI, Nevada
CHRIS STEWART, Utah
E. SCOTT RIGELL, Virginia
DAVID W. JOLLY, Florida
DAVID YOUNG, Iowa
EVAN H. JENKINS, West Virginia
STEVEN M. PALAZZO, Mississippi

NITA M. LOWEY, New York
MARCY KAPTUR, Ohio
PETER J. VISCLOSKY, Indiana
JOSÉ E. SERRANO, New York
ROSA L. DELAURO, Connecticut
DAVID E. PRICE, North Carolina
LUCILLE ROYBAL-ALLARD, California
SAM FARR, California
CHAKA FATTAH, Pennsylvania
SANFORD D. BISHOP, JR., Georgia
BARBARA LEE, California
MICHAEL M. HONDA, California
BETTY MCCOLLUM, Minnesota
STEVE ISRAEL, New York
TIM RYAN, Ohio
C. A. DUTCH RUPPERSBERGER, Maryland
DEBBIE WASSERMAN SCHULTZ, Florida
HENRY CUELLAR, Texas
CHELLIE PINGREE, Maine
MIKE QUIGLEY, Illinois
DEREK KILMER, Washington

WILLIAM E. SMITH, *Clerk and Staff Director*

CYSTIC FIBROSIS FOUNDATION
ADDING TOMORROWS

Submitted by: Preston W. Campbell, III, MD., President and CEO, Cystic Fibrosis Foundation

On behalf of the Cystic Fibrosis Foundation (CFF) and the 30,000 people with cystic fibrosis (CF) in the United States, we submit the following testimony to the House Appropriations Committee's Subcommittee on Labor, Health and Human Services, Education, and Related Agencies on our funding requests for fiscal year 2017. The Foundation requests funding levels of at least $34.5 billion for the National Institutes of Health (NIH) for the coming year. We encourage special consideration and support for the National Center for Advancing Translational Sciences (NCATS) and programs under its jurisdiction, including the Cures Acceleration Network (CAN) and the Clinical and Translational Science Awards (CTSA) as well as the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK), the National Institute of General Medical Sciences (NIGMS), and the National Heart, Lung, and Blood Institute (NHLBI), all of which play a vital role in CF research.

We also recommend that the Committee provide robust resources to the Health Resources and Services Administration (HRSA) and the Centers for Disease Control and Prevention (CDC), particularly their work to support nationwide newborn screening programs. Further, we urge the Committee to provide ample funding for the Center for Medicare and Medicaid Innovation (CMMI) to allow this agency the resources to update and streamline payment systems as well as the provision of robust resources for the Agency for Healthcare Research and Quality (AHRQ) and the Patient-Centered Outcomes Research Institute (PCORI).

Consistent, Robust Funding for NIH is Critical for American Research

The National Institutes of Health is a showcase for American ingenuity and a shining example of our country's generational legacy. NIH effectively uses appropriated funds to promote basic research and encourage collaboration across academic and commercial sectors to develop the building blocks of drug development. Basic research is a vital prerequisite for the discovery of new treatments and cures, and consistent, robust funding for NIH is crucial to support efforts that are developing novel therapies for serious and life threatening diseases.

The NIH received a $2 billion budget increase in fiscal year 2016, and it is critical that this momentum continue in this year's appropriations process. Researchers need consistent, reliable funding to run successful laboratories and plan long-term projects. Further, this one-time increase has not overcome the devastating and lasting effects of many years of sequestration and stagnant funding on American research labs both at the NIH and in collaborative programs across the country. Funding success rates for all investigators remain below sustainable levels, and promising young investigators struggle to obtain sufficient funding to remain in the field. The result has been a marked erosion of the US biomedical infrastructure.

Cuts to funding at the NIH have been detrimental to those seeking support for cystic fibrosis research. Large Center Core Grants, awarded by the NIDDK, support shared resources and facilities for use by multiple investigators and provide much needed funding for clinical and basic cystic fibrosis research centers. The funding increase in fiscal year 2016 has provided much needed financial relief for these programs, but if this momentum does not continue, large centers may be at risk of losing research programs and infrastructure. This is both detrimental to the individual centers and causes immense interruption and uncertainty in CF research overall.

Additionally, work performed at the NIH has had large benefits for the US economy. The agency supports more than 400,000 jobs across the country, and a report by Families USA

estimates every $1 of NIH funding generates more than double that in local economic growth. Increased investment in this agency can provide even greater economic payoff and support for the scientific progress that makes the United States the worldwide leader in biomedical research.

Research at NIH Supports Advances in CF Therapeutics

As the Committee considers its funding priorities for the coming fiscal year, we urge consideration of the critical role that NIH plays in the development of treatments for cystic fibrosis and other rare diseases. NIH-funded advances in fundamental cellular and molecular processes, such as the mapping of the human genome, and the development of high throughput screening were essential for the creation of two therapies that have been approved to treat the underlying cause of CF in more than 50% of those with the disease. These breakthrough drugs, Kalydeco and Orkambi, developed by Vertex Pharmaceuticals with significant support from the CF Foundation, relied heavily on discoveries funded by the NIH.

More exciting advancements are in the pipeline, and the Foundation is supporting 45 studies in 2016, including examination of several new genetically targeted therapies. Robust NIH funding is critical to maintain innovation in basic research and ensure a full pipeline of efficacious and affordable therapies for those with CF.

In particular, we urge the committee to support funding for behavioral research, especially with regard to treatment adherence in chronic conditions like CF. Cystic fibrosis is a progressive condition with complex treatment regimens that often require several hours per day. Adherence research can help those with CF optimize the efficacy of available treatments.

NIH Collaboration Promotes Cost-Efficient Research

Research supported by the NIH takes place at thousands of institutions across the country, and support of funding for the agency is a vital and effective way to foster collaboration among public and private stakeholders and allows for an efficient, well-funded research process. The CF Foundation collaborates with the NIH to fund and organize a number of research initiatives. For example, the OPTIMIZE study, which receives joint funding from the NIH and the CF Foundation, has brought together hospital systems in nearly 30 states to compare efficacy of antibiotic treatments for lung infections in those with cystic fibrosis. The CF Foundation urges the committee to allow expansion of cost-effective and efficient collaboration nationwide by providing funding for the NIH to continue growing its efforts.

NIH and the CF Foundation also jointly fund a research program at the University of Iowa to study the effects of CF in a pig model. The program is yielding fundamental new insights to help advance developments in the search for a cure. The University of Alabama has also developed a CF rat model using joint funding from NIH and the Foundation to examine methods for studying basic mechanisms and treatment of the disease.

We also urge the Committee to support collaboration through the expansion of research networks, such as NIH's Childhood Liver Disease Research Network (ChiLDReN) consortium at the NIDDK. This collaboration helps researchers discover treatments not only for CF liver disease but for other diseases that affect thousands of children each year.

The CF Foundation also urges the Committee to support and facilitate collaborative efforts by the FDA and NIH, such as the Regulatory Science Initiative and programs that allow for the placement of employees who will be engaged part-time at FDA and part-time at the NIH. The Foundation additionally encourages the creation of collaborative workshops with the NIH

and FDA to promote pediatric drug development and novel methodologies to streamline the research and development process.

Supporting the Next Generation of Researchers

We strongly urge the Committee to provide robust resources for the NIH to support the next generation of researchers. Recruiting and retaining a strong scientific workforce, especially in the area of pediatric specialties is critical in the fight to find a cure for CF and countless other diseases for which there are not adequate treatment options. Challenges in this area include recruiting new researchers to the CF field, ensuring funding for promising work, and retaining talented researchers who are committed to research careers. Again, this will simply not happen without sustained support and infrastructure that is supported by the NIH

The Precision Medicine Initiative

There are more than 1800 mutations within the CF gene that are linked to the underlying cause of CF, and with the advent of precision medicine, therapies like Kalydeco™ and Orkambi™ are being customized to treat a patient's genetic makeup. We urge the Committee to support the President's Precision Medicine Initiative by providing robust funding to the NIH to spearhead the development of new therapies that target the genetic cause of serious diseases. The CF Foundation urges the NIH to adopt precision medicine as a focus in an array of applicable areas, but this powerful initiative can only be possible through federal funding and resources.

Prioritizing a Centralized Institutional Review Board

Trials evaluating CF therapies are multi-site studies that can be slowed by repetitive review of local institutional review boards (IRBs). We commend the National Institutes of Health (NIH) for publishing and seeking comment on a policy that is intended to produce efficiencies in the clinical trials process while still protecting research participants by centralizing and simplifying the rigorous clinical trial review process. The CF Foundation sees the NIH as the logical choice to lead the centralization of institutional review boards and requests that the Committee take special consideration of the funds needed to implement this valuable initiative. At a time when research resources are restrained, efforts to reduce redundancy and improve efficiency in research are of the utmost importance.

Advancing Translational Science at the NIH

The Foundation requests robust funding for NIH's National Center for Advancing Translational Sciences (NCATS), which catalyzes innovation by improving the diagnostics and therapeutics development process and removing obstacles to translating basic scientific research into treatments. Research in dissemination and implementation science that focuses on integrating scientific findings and effective clinical practice into real-world service settings is crucial to providing the best possible care to those with CF and other conditions.

The specific programs housed in NCATS are integral to this mission, including the Clinical and Translational Science Awards (CTSA), the Cures Acceleration Network (CAN), and the Therapeutics for Rare and Neglected Diseases (TRND) program. Such initiatives transform the way in which clinical and translational research is conducted and funded. NIH Director Dr. Francis Collins has cited the CF Foundation's Therapeutics Development Network (TDN) as a model for TRND's innovative therapeutics development model.

Clinical Trial Data Sharing

The CF Foundation is enthusiastic about the potential for clinical trial, clinical care, claims, and other health care-related data to be used to advance drug discovery and development. The Foundation has been a pioneer in the advancement and utilization of a robust data repository through the CF Patient Registry, and our Therapeutics Development Network (TDN) has successfully encouraged clinical partners to share data. We ask that Congress support efforts by the NIH to explore strategies and guidelines for clinical trial data sharing. As drug development research advances, data sharing is vital to the acceleration of new discovery.

Supporting Greater Access to Quality Health Care

The CF Care Center Network is a model of quality, coordinated care that can be used as an example by policymakers and the rare disease community. We urge the Committee to allow greater access to this specialized care network by providing adequate resources and support for the Center for Medicare and Medicaid Innovation (CMMI) and their work to promote affordable access to specialized care. We also encourage funding for programs and agencies that promote research in health care quality and systems as well as clinical effectiveness and patient reported outcomes, including the Agency for Healthcare Research and Quality (AHRQ) and Patient-Centered Outcomes Research Institute (PCORI).

Nationwide Newborn Screening Programs

Newborn screening is critically important to the CF community because it allows for the early detection and treatment of symptoms as well as early use of CF modulator therapies, which can significantly reduce cumulative damage caused by the disease. The Foundation urges the Committee to provide ample funding for HRSA, which evaluates the effectiveness of newborn screening and follow-up programs and provides grants for programs to support other critical aspects of newborn screening. We also encourage the Committee to provide adequate funding to the CDC, which is responsible for strengthening and enhancing laboratory quality assurance programs; enabling public health laboratories to develop and refine screening tests; conducting pilot studies; implementing new methods to improve detection of treatable disorders; and enhancing newborn disorder detection through the Innovative Molecular Quality Program.

Conclusion

Cystic fibrosis is a rare genetic disease that causes the body to produce thick mucus that clogs the lungs and other bodily systems, resulting in life-threatening infections, diabetes, malnutrition, and other medical complications. This is a time of great hope and optimism for the CF community and those with other rare diseases as more research is being conducted to effectively treat these life threatening conditions. We urge you to provide at least $34.5 billion for the National Institutes of Health as well as robust funding for other relevant agencies to support and expand work already being done in biomedical programs and translational science and encourage cost-efficient collaboration of varied experts and stakeholders.

We stand ready to work with the Committee and Congressional leaders on the challenges ahead. Thank you for your consideration.

William L. Dewey, Ph.D.
Professor and Chair
Virginia Commonwealth University Department of Pharmacology and Toxicology
The College on Problems of Drug Dependence

Mr. Chairman and Members of the Subcommittee, thank you for the opportunity to submit testimony to the Subcommittee in support of the research funded by 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 United States addressing problems of drug dependence and abuse. The organization serves as an interface among governmental, industrial and academic communities maintaining liaisons with regulatory and research agencies as well as educational, treatment, and prevention facilities in the drug abuse field. Recognizing that so many health research issues are inter-related, we request that the subcommittee provide at least $34.5 billion for the National Institutes of Health (NIH) and within that amount a proportionate increase for the National Institute on Drug Abuse, in your Fiscal 2017 Labor, Health and Human Services, Education and Related Agencies Appropriations bill. We also respectfully request the inclusion of the following NIDA specific report language.

Opioid Misuse and Addiction. *The Committee is concerned about the escalating epidemic of prescription opioid and heroin use, addiction and overdose in the U.S. Nearly 130 people die each day in this country from opioid overdose, making it one of the most common causes of death for adolescents and young adults. The Committee appreciates the important role that research can and should play in the various federal initiatives aimed at this crisis. The Committee urges NIDA to 1) continue funding research on medications to alleviate pain, including the development of those with reduced abuse liability; 2) as appropriate, work with private companies to fund innovative research into such medications; and 3) report on what we know regarding the transition from opioid analgesics to heroin abuse and addiction within affected populations.*

Adolescent Brain Development. *The Committee recognizes and supports the Adolescent Brain and Cognitive Development (ABCD) Study. We know that the brain continues to develop into the mid-twenties. However, we do not yet know enough about the dramatic brain development that takes place during adolescence and how the various experiences children are exposed to during this time (e.g., sports injuries, lack of sleep, marijuana or other substance use) interact with each other and a child's biology to affect brain development and, ultimately, social, behavioral, health and other outcomes. As part of the Collaborative Research on Addiction (CRAN), a trans-NIH consortium involving NIDA, NIAAA, and NCI, and in partnership with NICHD, NINDS, NIMH, NIMHD, and OBSSR, the ABCD study intends to address this knowledge gap. As the largest ever longitudinal brain-imaging study of youth, the ABCD study will follow approximately 10,000 U.S. children from ages 9-10 into early adulthood, who will provide behavioral, neuroimaging, genetic, and other health data throughout development. The ABCD study will yield critical insights into the foundational aspects of adolescence that shape life trajectories. The committee also recommends and recognizes that the cost of this comprehensive study should not inhibit investigator initiated studies or any potential special appropriation for its ongoing support.*

Marijuana Research. *The Committee is concerned that marijuana public policies in the states (medical marijuana, recreational use, etc.) are being changed without the benefit of scientific research to help guide those decisions. The Committee is also concerned that restrictions associated with Schedule 1 of the Controlled Substance Act effectively limit the amount or type of research that can be conducted on marijuana or its component chemicals. NIDA is encouraged to continue supporting a full range of research on the effects of marijuana and its components, including policy research focused on policy change and implementation across the country. The Committee also directs NIDA to provide a short report on the barriers to research that result from the classification of marijuana as a Schedule 1 substance.*

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. Through its NIDAMeD initiative, NIDA is advancing addiction awareness, prevention, and treatment in primary care practices through seven Centers of Excellence for Physician Information. Intended to serve as national models, these centers target physicians-in-training, including medical students and resident physicians in primary care specialties (*e.g., *internal medicine, family practice, and pediatrics). NIDA also developed, in partnership with the Office of National Drug Control Policy, two online continuing medical education courses on safe prescribing for pain and managing patients who abuse prescription opioids. These courses were viewed by over 200,000 individuals and completed for credit by over 100,000 clinicians combined. The Committee continues to be pleased with NIDAMed, and urges the Institute to continue its focus on activities to provide physicians and other medical professionals with the tools and skills needed to incorporate drug abuse screening and treatment into their clinical practices.*

Medications Development. *The Committee recognizes that new technologies are required for the development of next-generation pharmaceuticals. In the context of NIDA funding, chief among these are NIDA's current approaches to develop viable immunotherapeutic or biologic (e.g., bioengineered enzymes) approaches for treating addiction. The goal of this research is the development of safe and effective vaccines or antibodies that target specific addictive drugs, like nicotine, cocaine, and heroin, or drug combinations. The Committee is encouraged by this approach - if successful, immunotherapies, alone or in combination with other medications, behavioral treatments, or enzymatic approaches, stand to revolutionize how we treat, and ultimately prevent addiction.*

Drug Treatment in Justice System Settings. *The Committee understands that providing evidence-based treatment for substance use disorders offers the best alternative for interrupting the drug use/criminal justice cycle for offenders with drug problems. Untreated substance using offenders are more likely to relapse into drug use and criminal behavior, jeopardizing public health and safety and taxing criminal justice system resources. Treatment has consistently been shown to reduce the costs associated with lost productivity, crime, and incarceration caused by drug use. This reality represents a significant opportunity to intervene with a high-risk population. In 2013 NIDA launched the Juvenile Justice Translational Research on Interventions for Adolescents in the Legal System (JJ-TRIALS) program to identify and test strategies for*

improving the delivery of evidence-based substance abuse and HIV prevention and treatment services for justice-involved youth. The JJ-TRIALS initiative will provide insight into the process by which juvenile justice and other service settings can successfully adopt and adapt existing evidence-based programs and strategies to improve treatment for at-risk youth. The Committee supports this important work and asks for a progress report in the next appropriations cycle.

Electronic Cigarettes. *The Committee understands that electronic cigarettes (e-cigarettes) are increasingly popular among adolescents. Lack of regulation, easy availability, and a wide array of cartridge flavors may make them particularly appealing to this age group. In addition to the unknown health effects, early evidence suggests that e-cigarette use may serve as an introductory product for youth who then go on to use other tobacco products, including conventional cigarettes, which are known to cause disease and lead to premature death. Early evidence also reveals that these devices are widely used as tools for smoking derivatives of marijuana (hash oil, "shatter," etc.) The Committee requests that NIDA fund research on the use and consequences of these devices.*

Drug abuse is costly to Americans; it ruins lives, while tearing at the fabric of our society and taking a huge financial toll on our resources. Beyond the unacceptably high rates of morbidity and mortality, drug abuse is often implicated in family disintegration, loss of employment, failure in school, domestic violence, child abuse, and other crimes. Placing dollar figures on the problem; smoking, alcohol and illegal drug use results in an exorbitant economic cost on our nation, estimated at over $600 billion annually. We know that many of these problems can be prevented entirely, and that the longer we can delay initiation of any use, the more successfully we mitigate future morbidity, mortality and economic burdens.

Over the past three decades, NIDA-supported research has revolutionized our understanding of addiction as a chronic, often-relapsing brain disease –this new knowledge has helped to correctly emphasize the fact that drug addiction is a serious public health issue that demands strategic solutions. By supporting research that reveals how drugs affect the brain and behavior and how multiple factors influence drug abuse and its consequences, scholars supported by NIDA continue to advance effective strategies to prevent people from ever using drugs and to treat them when they cannot stop.

NIDA supports a comprehensive research portfolio that spans the continuum of basic neuroscience, behavior and genetics research through medications development and applied health services research and epidemiology. While supporting research on the positive effects of evidence-based prevention and treatment approaches, NIDA also recognizes the need to keep pace with emerging problems. We have seen encouraging trends – significant declines in a wide array of youth drug use -- over the past several years that we think are due, at least in part, to NIDA's public education and awareness efforts. However, areas of significant concern include the recent increase in lethalities due to heroin and synthetic fentanyl, as well as the continued abuse of prescription opioids and the recent increase in availability of designer drugs and their deleterious effects. The need to increase our knowledge about the effects of marijuana is most important now that decisions are being made about its approval for medical use and/or its legalization. We support NIDA in its efforts to find successful approaches to these difficult problems.

The nation's previous investment in scientific research to further understand the effects of abused drugs on the body has increased our ability to prevent and treat addiction. As with other diseases, much more needs be done to improve prevention and treatment of these dangerous and costly diseases. Our knowledge of how drugs work in the brain, their health consequences, how to treat people already addicted, and what constitutes effective prevention strategies has increased dramatically due to support of this research. However, since the number of individuals continuing to be affected is still rising, we need to continue the work until this disease is both prevented and eliminated from society.

We understand that the FY2017 budget cycle will involve setting priorities and accepting compromise, however, in the current climate we believe a focus on substance abuse and addiction, which according to the World Health Organization account for nearly 20 percent of disabilities among 15-44 year olds, deserves to be prioritized accordingly. We look forward to working with you to make this a reality. Thank you for your support for the National Institute on Drug Abuse.

Medical Library Association and Association of Academic Health Sciences Libraries Statement on FY17 Appropriations for the National Library of Medicine Submitted to the House Subcommittee on L-HHS, Education & Related Agencies

INTRODUCTION

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). 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 $395,110,000 for NLM in FY17.

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 results of research readily available to all who need it. As health sciences librarians who use NLM's programs and services every day, we can attest that these resources literally save lives making NLM an investment in good health.

NLM Leverages NIH Investments in Biomedical Research

In today's challenging budget environment, we recognize the difficult decisions Congress faces as it works to improve our nation's fiscal stability. We thank the Subcommittee for its long-standing commitment to strengthening NLM's budget. NLM's budget supports intramural services and programs that sustain the nation's biomedical research enterprise and more—it builds, sustains, and augments NLM's suite of more than 200 databases which provide information access to health professionals, researchers, educators, and the public. NLM's budget also supports all aspects of library operations and programs, including the acquisition, organization, preservation, and dissemination of the world's biomedical literature, no matter the medium.

In FY17 and beyond, it is critical to continue augmenting NLM's baseline budget to support expansion of its information resources, services, and programs which collect, organize, and make readily accessible rapidly expanding biomedical knowledge resources and data. NLM maximizes the return on the investment in research conducted by the NIH and other organizations. The Library makes the results of biomedical information more 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 is a leader in Big Data and plays a critical role in accelerating nationwide deployment of health information technology, including electronic health records (EHRs), by leading the development, maintenance and dissemination of key standards for health data interchange that are now required of certified EHRs. NLM also contributes to Congressional priorities related to drug safety through expansion of its clinical trial registry and results database (ClinicalTrials.gov) in response to legislative requirements, and to the nation's ability to prepare for and respond to disasters.

Growing Demand for NLM's Basic Services
NLM delivers more than 50 trillion bytes of data to millions of users daily that helps researchers advance scientific discovery and accelerate its translation into new therapies; provides health practitioners with information that improves medical care and lowers its costs; and gives the public access to resources and tools that promote wellness and disease prevention. Every day, medical librarians across the nation use NLM services to assist clinicians, students, researchers, and the public in accessing information they need to save lives and improve health. Without NLM, our nation's medical libraries would be unable to provide the 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, Genetics Home Reference (GHR), PubMed, and PubMed Central are revolutionizing medicine and ushering in an era of personalized medicine in which care is based on an individual's unique genetic profile. GenBank is the definitive source of gene sequence information. More than 2.2 million users accessed consumer-level information about genetics from GHR which contains 2,649 summaries of genetic conditions, genes, gene families, and chromosomes. PubMed, with more than 25 million references to the biomedical literature, is the world's most heavily used source of bibliographic information. Approximately 806,000 new citations were added in FY16, and the database provided high quality medical information to more than 2 million users each day. PubMed Central is NLM's digital archive which provides public access to the full-text versions of more than 3.6 million biomedical journal articles, including those produced by NIH-funded researchers. On a typical weekday more than one million users download more than 2 million full-text articles, including those submitted in compliance with the NIH Public Access Policy.

As the world's largest and most comprehensive medical library, NLM's traditional print and electronic collections continue to steadily increase each year, standing at more than 21 million items—books, journals, technical reports, manuscripts, microfilms, photographs and images. By selecting, organizing and ensuring permanent access to health sciences information in all formats, NLM ensures the availability of this information for future generations, making it accessible to all Americans, irrespective of geography or ability to pay, and guaranteeing that citizens can make the best, most informed decisions about their healthcare.

Encourage NLM Partnerships
NLM's outreach programs are essential to MLA and AAHSL membership and to the profession. Through the National Network of Libraries of Medicine (NN/LM), with over 6,400 members in communities nationwide, the NN/LM educates medical librarians, health professionals and the general public about NLM's services and trains them in the most effective use of these services. Beginning with the 2016-2021 funding cycle, the NN/LM includes Coordinating Offices that will independently support Network activities by providing technical expertise, planning, and coordination, and serve as the Network's central point of contact to reduce redundancy of effort throughout the Network.

The NN/LM serves the public by promoting educational outreach for public libraries, secondary schools, senior eenters and other consumer-based settings, and its emphasis on outreach to underserved populations helps reduce health disparities among large sections of the American public. NLM's "Partners in Information Access" program improves access by local public health officials to information which prevents, identifies and responds to public health threats and

ensures every public worker has electronic health information services that protect the public's health.

NLM's MedlinePlus provides consumers with trusted, reliable health information on more than 900 topics in English and Spanish. It has become a top destination for those seeking information on the Internet, attracting more than 3 million visitors daily. NLM has continued to make enhancements to MedlinePlus, with selected materials now available in forty other languages. New versions of MedlinePlus and MedlinePlus en español have been released and have been optimized for easier use on mobile phones and tablets. Other products and services that benefit public health and wellness include the *NIH MedlinePlus Magazine* and *NIH MedlinePlus Salud,* available in doctors' offices nationwide, and NLM's MedlinePlus Connect—a utility which enables clinical care organizations to implement links from their electronic health records systems to relevant patient education materials in MedlinePlus.

MLA and AAHSL applaud the success of NLM's outreach initiatives, and we look forward to continuing to work with NLM on these programs.

Emergency Preparedness and Response

Through its Disaster Information Management Research Center, NLM 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 information on bioterrorism, chemical emergencies, fires and wildfires, earthquakes, tornadoes, and pandemic disease outbreaks. MLA and NLM continue to develop the Disaster Information Specialization (DIS) program to build the capacity of librarians and other interested professionals to provide disaster-related health information outreach. Working with libraries and publishers, NLM's Emergency Access Initiative makes available free full-text articles from hundreds of biomedical journals and reference books for use by medical teams responding to disasters. MLA and AAHSL ask the Subcommittee to support NLM's role in this crucial area which ensures continuous access to health information and use of libraries and librarians when disasters occur. NLM has created a comprehensive Web page to gather resources on emerging health issues arising from the Zika Virus. Many medical libraries include links to it on their Web sites. This is another example of the fine work that NLM does on behalf of the public.

In 2015, NLM and the Health and Human Services Office of the Assistant Secretary for Preparedness and Response released a new version of the Radiation Emergency Medical Management (REMM) website which gives health care personnel key information about the diagnosis and treatment of radiation injuries and access to interactive clinical tools and data. The site provides just-in-time, evidence-based, usable information with sufficient background and context to make complex issues understandable to health providers without formal training or expertise in radiation medicine.

Health Information Technology and Bioinformatics

For more than 40 years, NLM has supported informatics research, training and the application of advanced computing and informatics to biomedical research and healthcare delivery including telemedicine projects. Many of today's biomedical informatics leaders are graduates of NLM-funded informatics research programs at universities nationwide. A number of the country's

exemplary electronic and personal health record systems benefit from findings developed with NLM grant support.

The importance of NLM's work in health information technology continues to grow as the nation moves toward more interoperable health information technology systems. A leader in supporting the development, maintenance, and dissemination of standard clinical terminologies for free nationwide use (e.g., SNOMED), NLM works closely with the Office of the National Coordinator for Health Information Technology to promote the adoption of interoperable electronic records, and has developed tools to make it easier for EHR developers and users to implement accepted health data standards in their systems and link to relevant patient education materials.

Dissemination of Clinical Trial Information

ClinicalTrials.gov, the world's largest clinical trials registry, was expanded in FY16, and now includes more than 212,000 registered studies and summary results for more than 21,000 trials, including many not available elsewhere. As health sciences librarians who fulfill requests for information from clinicians, scientists, and patients, we applaud the NIH and NLM for their efforts to expand and clarify the regulations for clinical trials registration and results submission, and for work to apply the ClinicalTrials.gov requirements to all NIH clinical trials. These efforts will enhance the transparency of clinical trial results, and provide patients with more information to make necessary health care decisions, including critical information about the safety of products and treatment options. Clinicians will have access to results information about efficacy, adverse effects, and safety; and biomedical researchers will have information on research design, safety, and scientific results that can inform future protocols and discoveries. We also support timely, easily understood, and accurate reporting of all clinical trials, especially those supported by federal funding, regardless of agency and phase of the clinical trial, and information about studies that have been terminated due to adverse events, difficulties in research design making accrual difficult, or simply feasibility problems. Ultimately, expanding the requirements will create an incredible and vastly important database of clinical data and knowledge for clinicians, scientists, and patients who need access to cutting-edge information.

In addition to these efforts, NLM recently launched MedPix®, a free online medical image database of 53,000 indexed and curated images, from over 13,000 patients. As a public education service, NLM and MedPix provide the storage space, indexing, and Web server hosting. Individuals as well as institutions may participate with no additional software required other than an Internet browser. The primary target audience includes physicians and nurses, allied health professionals, medical students, nursing students and others, and will include a continuing medical education module in the near future.

Improving Public Access to Funded Research Results

Last year, the Department of Health and Human Services (DHHS) announced it plans and common policy approach to expanding public access to the results of scientific research funded by HHS agencies. Its operating divisions (Agency for Healthcare Research and Quality, Centers for Disease Control, Food and Drug Administration, and NIH) as well as the Assistant Secretary for Preparedness and Response will utilize NLM's PubMed Central as the common repository for its peer-reviewed publications and PubMed, a repository of citations, for the sharing of

metadata. NLM's experience in developing these systems and related tools and engaging the health sciences library community in outreach will be essential to effective implementation of HSS-wide policies and improving compliance.

Thank you again for the opportunity to present our views. As health sciences librarians who use NLM's products and services, and as intermediaries who serve the information needs of researchers, clinicians, and the public, we value and rely upon the high quality resources, services, and leadership that NLM provides in support of our nation's health professionals, educators, researchers, and the public. As the needs of these audiences continue to evolve, we are confident that NLM's vision and understanding of the role of information, data, and technology will continue to fuel the development of just-in-time resources and tools that will keep our nation's health, biomedical, and scientific professionals at the forefront of health care, discovery, and innovation.

We look forward to continuing this dialogue and supporting the Subcommittee's efforts to secure the highest possible funding level for NLM in FY17 and the years beyond to support the Library's mission and growing responsibilities.

SUMMARY OF FISCAL YEAR 2017 RECOMMENDATIONS

- Continue the commitment to the National Library of Medicine (NLM) by supporting the President's budget proposal which requests $395,110,000.
- Continue to support the medical library community's role in NLM's outreach, telemedicine, disaster preparedness, health information technology initiatives, and health care reform implementation.

Organizational Bios

The Medical Library Association (MLA) is a nonprofit, educational organization with 3,500 health sciences information professional members worldwide. Founded in 1898, MLA provides lifelong educational opportunities, supports a knowledgebase of health information research, and works with a global network of partners to promote the importance of quality information for improved health to the health care community and the public.

The Association of Academic Health Sciences Libraries (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.

ADEA | THE VOICE OF DENTAL EDUCATION

Testimony of the American Dental Education Association
Submitted for the Record
Subcommittee on Labor, Health and Human Services, Education, and Related Agencies
Committee on Appropriations
United States Congress

The American Dental Education Association (ADEA) represents all 66 U.S. dental schools, 700 dental residency training programs, nearly 600 allied dental programs, as well as more than 12,000 faculty who educate and train the nearly 50,000 students and residents attending these institutions. ADEA submits this testimony for the record and for your consideration as you begin prioritizing fiscal year 2017 appropriation requests.

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

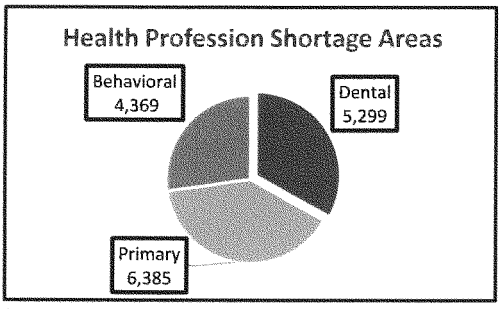
ADEA's academic dental institutions educate and train future oral health providers and dental and craniofacial researchers. As one of the largest safety-net providers of dental care in the United States, these dental schools provide significant care to the uninsured and underserved populations. Given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

ADEA urges you to adequately fund and protect funding for Title VII of the Public Health Service Act and the National Institute of Dental and Craniofacial Research (NIDCR). Title VII, through its various grants and programs, facilitates access to dental care to millions of Americans and NIDCR fosters globally recognized cutting-edge dental and craniofacial research.

Specifically, we are requesting funding for the following: 1) Title VII of the Public Health Service Act; 2) National Institute of Dental and Craniofacial Research (NIDCR); 3) Centers for Disease Control and Prevention (CDC), Division of Oral Health; 4) Ryan White HIV/AIDS Treatment and Modernization Act, Part F: Dental Reimbursement Program (DRP) and the Community-Based Dental Partnerships Program.

As you deliberate funding for FY 2017, ADEA respectfully makes the following funding requests:

I. $35.9 million: Title VII, Section 748, Public Health Service Act



The dental programs in Title VII, Section 748 of the Public Health Service Act, provide critical training in general, pediatric and public health dentistry and dental hygiene. Support for these programs will help ensure an adequately prepared dental workforce. The funding supports predoctoral dental education and postdoctoral pediatric, general and public health dentistry residency training. The investment made by Title VII not only educates dentists, dental therapists and dental hygienists, but also expands access to care for underserved communities since much of the care is provided in community-based settings located in health profession shortage areas.

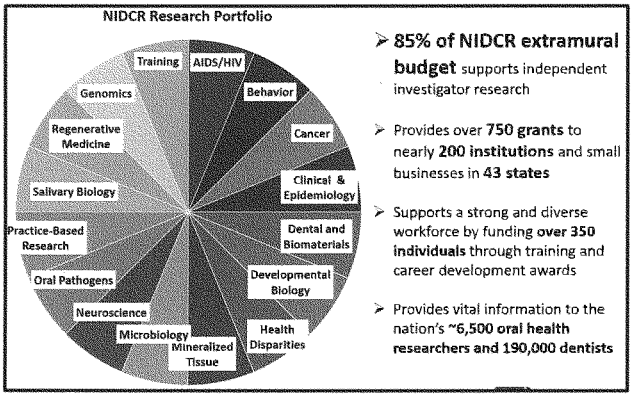
Additionally, Section 748 addresses the shortage of professors in dental schools with the dental faculty loan repayment program and faculty development courses for those who teach pediatric, general or public health dentistry and dental hygiene. There are currently more than 200 open, budgeted faculty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

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

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

ADEA is most concerned that the Administration did not request any funds for the Area Health Education Centers (AHEC) program. This vital program is targeted at enhancing high quality, culturally competent care in community-based interprofessional clinical training settings. The infrastructure development grants and point of service maintenance and expansion grants ensure that patients from underserved populations receive quality care and that health professionals receive training with diverse populations. ADEA strongly encourages the Committee to continue funding the vitally important AHEC program.

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



Dental research serves as the foundation of the profession of dentistry. Discoveries stemming from dental research have reduced the burden of oral diseases, led to better dental health for millions of Americans and uncovered important links between oral and systemic health. ADEA and dental school researchers are grateful for the increase NIDCR received in FY 2015, however the increased funding was allocated to required NIH-wide initiatives. The requested increase will provide for a six percent real growth to ensure continued growth of the *Precision Medicine Initiative* and progress to meet the goals outlined in the 21st Century Cares Act and the Biomedical Innovation Agenda legislation currently being debated by Congress. Through NIDCR grants, dental researchers in academic dental institutions have enhanced the quality of the nation's dental and overall health. Dental researchers are poised to make dramatic breakthroughs, such as restoring natural form and function to the mouth and face as a result of disease, accident, or injury; and diagnosing systemic disease (such as HIV and certain types of cancer) from saliva instead of blood and urine samples. These breakthroughs and countless others, which continue America's role as a global scientific leader, require adequate funding.

III. $19 million: Centers for Disease Control and Prevention (CDC) Division of Oral Health

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

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

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

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

Please use ADEA as a resource on any matter pertaining to dental education and training of the dental workforce under your purview. For additional information contact: Yvonne Knight, J.D., ADEA Chief Advocacy Officer at Knighty@adea.org or (202) 513-1165.

Arthur Schlesinger
Chair
Ohio Statewide Independent Living Council (OSILC)

Prepared for the Subcommittee on Labor, Health and Human Services, and Education and Related Agencies.
This testimony is addressing Health and Human Services (HHS)

I am writing on behalf of the Ohio Statewide Independent Living Council, Ohioans with Disabilities and the 12 Centers for Independent Living (CILs) throughout the State of Ohio. We join with the National Council of Independent Living (NCIL) to support the request for increased funding of $200 million for the Independent Living line item in the Federal Fiscal Year 2017 appropriations budget by the Department of Health and Human Services. The $200 million would increase the IL line item to $301 million and would help reaffirm Congress' commitment to the more than 57 million Americans with Disabilities.

CILs are cross-disability, non-residential, community-based, non-profit organizations that are designed and operated by individuals with disabilities. CILs are unique in that they are directly governed and staffed by people with all types of disabilities, including people with mental, physical, sensory, cognitive, and developmental disabilities. Each of the 365 federally funded centers provides five core services: information and referral, individual and systems advocacy, peer support, independent living skills training, and transition services, which were added with the passage of the Workforce Innovation and Opportunity Act (WIOA). From 2012-2014, CILs provided the core services to nearly 5 million people with disabilities, and provided additional services such as housing assistance, transportation, personal care attendants, and employment services to hundreds of thousands of individuals. During this same period, prior to transition being added as a core service, CILs transitioned 13,030 people with disabilities from nursing homes and other institutions into the community. Since 2008 Ohio has transitioned 7,739 individuals from institutional settings into the community, and nearly 2000 of those transitions were accomplished by Ohio CILs.

Transition services were added as a fifth core service with the 2014 reauthorization of the Rehabilitation Act within the Workforce Innovation and Opportunity Act. Transition services include the transition of individuals with significant disabilities from nursing homes and other institutions to home and community-based residences with appropriate supports and services, assistance to individuals with significant disabilities at risk of entering institutions to remain in the community, and the transition of youth with significant disabilities to postsecondary life. This core service is vital to achieving full participation for people with disabilities.

Every day CILs are fighting to ensure that people with disabilities gain and maintain control over our own lives. We know that this cannot occur when people reside in institutional settings. Opponents of deinstitutionalization say that allowing people with disabilities to live in the

community will result in harm. We know that the 13,030 people with disabilities who CILs successfully transitioned out of nursing homes and institutions from 2012-2014 prove otherwise. Additionally, when services are delivered in an individual's home, the result is a tremendous cost savings to Medicaid, Medicare, and states. Community-based services enable people with disabilities to become less reliant on long-term government supports, and they are significantly less expensive than nursing home placements. We are grateful that Congress demonstrated their understanding and support for community-based services when WIOA was passed and transition was added as a fifth core service.

Since transition services were added as a core service, the need for funding is critical. Moreover, CILs need additional funding to restore the devastating cuts to the Independent Living program, make up for inflation costs, and address the increased demand for independent living services. In 2016, the Independent Living Program is receiving $2.5 million less in funding than it was in 2010. It is simply not possible to meet the increasing demand for services and effectively provide transition services without additional funding. Increased funding should be reinvested from the billions currently spent to keep people with disabilities in costly Medicaid nursing homes and institutions and out of mainstream society.

Centers for Independent Living play a crucial role in the lives of people with disabilities, and work tirelessly to ensure that people with disabilities have a real choice in where and how they live, work and participate in the community. Additionally, CILs are an excellent service and a bargain for America, keeping people engaged with their communities and saving taxpayer money. NCIL is dedicated to increasing the availability of the invaluable and extremely cost-effective services CILs provide, and they have submitted written testimony with a similar request. I strongly support NCIL's testimony.

April 15th, 2016

Testimony of Susan Ruzenski
Executive Director
Helen Keller National Center, Sands Point, NY

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 Subcommittees in the House and Senate. **The Center requests an increase of $4.7 million from its current $10.3 million to $15 million in funding for FY 2017.**

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 his/her 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:

(1) 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;
(2) 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.
(3) Train professionals and allied personnel at the Center or anywhere else in the United States to provide services to the deaf-blind.
(4) Conduct applied research, development programs, and demonstrations with respect to communication techniques, teaching methods, aids and devices, and delivery of services;
(5) Maintain a national registry of individuals who are Deaf-Blind.

The year 2017 marks HKNC's fiftieth year as a national resource. HKNC is striving to fulfill its congressional mandate by: operating a comprehensive rehabilitation training program at its headquarters in Sands Point, NY; providing technical assistance, information, referral, advocacy, and training to local communities through its ten (10) regional offices and outreach programs; enhancing the ability of service providers to better meet the needs of people who are deaf-blind at the state and local levels by sponsoring research, disseminating information, and offering training to professionals nationwide.

HKNC has been level-funded for nearly 16 years. In the FY 2016 appropriations act HKNC was granted an increase of $1.2 million by the Committee for which we are most grateful. But a critical need remains for HKNC to receive an annual appropriation of $15 million in FY 2017 to ensure that American citizens who are deaf-blind are provided with training opportunities that will promote their success, independence and full participation in their communities and for HKNC to fully meet its congressional mandate.

The lack of funding to over many years to cover even moderate inflation of costs has affected services and some aspects of national service delivery. Fulfillment of our mission requires an investment by the federal government not only to restore capacity, but to grow and strengthen to become the national resource it was intended to be. Over the long period of level funding HKNC had to eliminate staff positions supporting the comprehensive vocational rehabilitation program, resulting in a one year waiting list for prospective participants. Fewer people are being served annually and, regrettably, a model program providing employment and life skills training to deaf-blind Americans with intellectual disabilities was discontinued. Further, due to the lack of funding resources, HKNC had to suspend its widely lauded national affiliate network of over 40 state and private agencies which was built over two decades. This had a negative impact on the building of a national infrastructure for deaf-blind services across the United States.

Presently there is a serious lack of qualified practitioners to meet the growing needs of all age groups of deaf-blind individuals including transition age youth, working age adults, and the burgeoning population of senior citizens.

In June of 2011, the WESTAT Corporation completed a two year evaluation of HKNC on behalf of the U.S. Department of Education's Rehabilitation Services Administration. Among its conclusions were that, "*HKNC [is] meeting its mandate to provide services to any deaf-blind individual, family members, and service providers, and conduct applied research and demonstrations*" and that, "*the preponderance of evidence from multiple data sources indicates that HKNC is providing services to address the vocational and independent living needs of deaf-blind individuals, and many stakeholders familiar with HKNC's work consider HKNC to be the 'gold standard' for provision of services to deaf-blind individuals.*" Additionally, the WESTAT evaluation indicated that state VR agencies generally lack services and resources for individuals who are deaf-blind, further reconfirming the necessity of HKNC's goal to build a national infrastructure. With increased funding HKNC can fortify the network of service providers nationwide and establish a sustainable infrastructure leading to exemplary practices and collaborative efforts in services, learning and research.

With the increased FY 2016 funding HKNC has taken steps toward development of an improved process to address the unmet needs of individuals with combined vision and hearing loss, their family members and vocational rehabilitation professionals. The former HKNC national affiliate network is being re-invented as the Helen Keller National Center's Deaf- Blind National Community of Practice (NCOP). With HKNC's leadership, a national network of local and state agencies will be able to initiate and expand existing services to the deaf-blind. Through this collaboration, these local and state agencies will maximize effectiveness and efficiency in learning and research. The Center will play the pivotal role disseminating resources among members of the NCOP and facilitate dialogue across professional disciplines. HKNC will require additional funding to expand field operations to implement this effort. The goal is to increase resources within the regions and leverage the national network by deploying twenty deaf-blind specialists throughout the regions to offer services, build collaborative teams working with consumers, their family members and service providers to successfully achieve vocational and independent living outcomes. HKNC and the national network will provide a wide array of services to America's deaf-blind citizens directly in their home communities, galvanize research efforts, increase sharing of expert knowledge and maximize resources. Greater federal

investment will permit HKNC to partner with researchers, universities, private and state agencies, and consumer organizations to rebuild capacity and to reestablish needed services on a local basis throughout the nation.

In collaboration with state vocational rehabilitation programs and the Mississippi State University Research and Training Center on Blindness and Low Vision, HKNC has conducted five state wide needs assessments and a variety of national surveys to identify professional learning needs across the United States. In response, the Center has developed training modules for vocational rehabilitation counselors, mental health professionals, Support Service Providers (SSPs), Adaptive Technology Trainers, Orientation and Mobility Instructors among others. HKNC continues to address the expressed needs of deaf-blind individuals with course development in self advocacy and Haptics, an innovative touch signal system that can provide optimal environmental access to individuals who are deaf-blind. The recent FY 2106 increase of $1.2 million enabled HKNC to maintain staff experts to carry out these essential projects. These can become the driving force for systematic change and capacity building across the country.

We can only continue this mission of building a national service delivery system that can touch the lives of deaf-blind individuals throughout the United States if given the resources commensurate with the scope and importance of the work to be done.

With a $4.7 million increase in funding we aim to:

(1) Maximize the effectiveness and outcomes of the Helen Keller National Center's Deaf-Blind National Community of Practice (NCOP) for service providers working with youth and adults who are deaf-blind.

(2) Replicate the HKNC Community Services Program, investing in four states to broaden and strengthen comprehensive and specialized service options by developing a core group of trained rehabilitation professionals in each. HKNC will strengthen its national collaborative approach to service delivery by expanding its workforce with two deaf-blind specialists in each region.

(3) Develop and offer an array of professional learning programs and products specifically designed to increase the number of trained professionals.

(4) Provide further research documenting needs, trends and best practices in the deaf-blind community.

(5) Maintain and enhance our capacity to offer comprehensive vocational rehabilitation services to a greater number of individuals on an annual basis.

Congressional leaders fifty years ago shared our commitment and vision for services to deaf-blind citizens. The Helen Keller National Center is at a critical moment in our history. The time has come for a national service delivery to be created so that all American citizens who are deaf-blind have an equal opportunity to live self-actualized lives as fully contributing and included members of their community.

Outside Written Testimony for the record from the
American Association for Cancer Research (AACR)
FY 2017 Appropriations for the National Institutes of Health
Subcommittee on Labor, Health and Human Services, Education and Related Agencies
Committee on Appropriations, United States House of Representatives
April 15, 2016

Submitted on behalf of: Margaret Foti, PhD, MD (hc), Chief Executive Officer
American Association for Cancer Research, 615 Chestnut Street, 17th Floor
Philadelphia, PA 19106; (215) 440-9300/fax (215) 440-9313; MaryLee.Watts@aacr.org

The American Association for Cancer Research (AACR) is the world's first and largest scientific organization focused on every aspect of high-quality, innovative cancer research. The mission of the AACR and its more than 35,000 members is to prevent and cure cancer through research, education, communication, and collaboration. **The AACR calls on Congress to provide at least $34.5 billion for the National Institutes of Health (NIH) in fiscal year (FY) 2017 (a 7.7% increase), and to provide a $680 million increase above FY 2016 levels for the National Cancer Institute (NCI) to initiate the National Cancer "Moonshot" Initiative.** Keeping the NIH and NCI on a path of sustained, robust, and predictable funding growth is the only way we will seize the unparalleled scientific opportunities in cancer research that lie before us, and the only way we will overcome the challenges we face in conquering this complex disease.

We thank the United States Congress for its longstanding, bipartisan support for the NIH and for its commitment to funding cancer research. We especially thank House Appropriations Subcommittee on Labor, Health and Human Services (HHS), Education Chairman Tom Cole and Ranking Member Rosa DeLauro for their unwavering support for the NIH. We are grateful for the $2 billion increase appropriated to the NIH in the FY 2016 omnibus spending bill, the most significant boost in a decade for the agency. Through Congress making medical research a national priority, federal funding for this lifesaving work has turned a corner and is once again headed in the right direction.

A Unique Moment for Cancer: Supporting the National Cancer "Moonshot" Initiative

We live in an extraordinary time of scientific opportunity in the field of cancer research. The AACR looks forward to continuing to work with Congress to accelerate progress against the more than 200 diseases we call cancer in the next five to ten years. To that end, the AACR strongly supports the National Cancer "Moonshot" Initiative. Now is the time for a major, new initiative cancer science that both supports and builds upon the strong, basic science foundation that has been established, and translates the exciting scientific discoveries into improved therapies for cancer patients. Nowhere is this more evident than in genomics, immuno-oncology and precision medicine, an area in which cancer research has been leading the way for more than a decade. A strong commitment to the NIH and the NCI is required to move this Initiative forward, in addition to continued support for existing NIH programs such as the Precision Medicine Initiative, which has an important oncology component.

Investments in Cancer Research are Saving and Improving Lives

Significant progress has been made against cancer because of the decades of federal investment in medical research and the dedicated work of researchers, physician-scientists, and patient advocates throughout the biomedical research ecosystem. Federal support has cultivated new and improved approaches to the prevention, detection, diagnosis, and treatment of cancer, and investments in basic research have enabled scientists to capitalize on the understanding of what causes and drives cancer. As is detailed in the *AACR Cancer Progress Report 2015*, support from the NIH and the NCI for basic, translational, and clinical research has led to decreases in the incidence of many cancers, cures for a number of these diseases, and higher quality and longer lives for many individuals whose cancers cannot yet be prevented or cured.

Consider the progress made *in just the last 18 months*. Cancer patients now have access to:

- 21 new anticancer therapeutics;
- 13 new uses for previously approved cancer drugs;
- 1 new use for an imaging agent;
- 1 new cancer screening test; and,
- 1 new cancer prevention vaccine.

One of the most exciting breakthroughs in the past five years in cancer research has been the ability to harness the power of a patient's own immune system to fight cancer, leading to the development of immunotherapies. The concept of immunotherapy as a means to target cancer cells is not new, but we now have achieved the ability to effectively translate decades of knowledge about the immune system into revolutionary advances in patient care. In 2015 alone, the FDA approved five cancer immunotherapies, including the first immunotherapies for lung cancer and for children with cancer.

Perhaps most illustrative of our progress is the fact there are now an estimated 14.5 million cancer survivors living today in the United States, and this number is expected to grow to 18 million by the year 2020. These remarkable achievements would never have been possible without a national commitment to funding cancer research, screening, and treatment programs at the NCI, NIH, and other agencies. We can continue to make significant advances, but only if we redouble our efforts to ensure the federal resources are there to continue, and increase, the pace of progress.

In addition to improving health and saving lives, cancer research and biomedical science also serves as one of our country's primary paths to innovation, global competitiveness, and economic growth. According to United for Medical Research, NIH funding directly and indirectly supported more than 402,000 jobs in 2012 alone, and generated more than $57.8 billion in new economic activity.

Lastly, conquering cancer is important to the American public. In a poll of eligible voters commissioned by the AACR last year, more than 80% of respondents recognized that progress was being made against cancer, but the progress was not happening quickly enough. The same poll showed that a majority of Americans (3 out of 4 individuals polled) support increasing federal funding for medical research.

Cancer remains a significant public health challenge

Even in the face of the promise and progress highlighted above, cancer remains a formidable opponent, and the 2015 AACR poll found that it remains the disease Americans fear most. An estimated 1.7 million Americans will be diagnosed with cancer this year, and 1 in every 3 women and 1 in every 2 men will likely develop cancer in their lifetimes. It is also projected that more than 595,000 people will die this year in the U.S. from cancers. There also are a number of cancers, including pancreatic, liver and lung cancers, for which the mortality rate remains extraordinarily high and 5-year survival rates are typically less than 50 percent. Further, racial and ethnic minorities, as well as low-income, rural and elderly populations, continue to suffer disproportionately in cancer incidence, prevalence, and mortality. Because of the steady increase in cancer incidence rates, which is due in part to our aging and growing minority populations, continuing and strengthening our nation's commitment to cancer research and biomedical

science is more critical now than ever. Increasing the federal investment in cancer research and biomedical science will play a vital role in addressing the current challenges in cancer, while at the same time curbing the overall annual costs of this devastating disease —the economic cost of which exceeded $263 billion in 2010 and is expected to continue to rise as the number of cancer deaths increases.

Progress against cancer requires a sustained commitment to funding

Our nation's ability to realize the exciting future that awaits us in cancer research depends on a continued, strong commitment by Congress to provide sustained, robust, and predictable funding increases for the NIH and the NCI. We have reached an inflection point, where discoveries are being made at an ever-accelerating pace. These discoveries are saving lives and bringing enormous hope for cancer patients, even those with advanced disease. We must seize the opportunity to continue to invest in our nation's medical research ecosystem **by providing at least $34.5 billion for the NIH in FY 2017. We also must make, as Vice President Biden said in October 2015, an "absolute national commitment to end cancer as we know it today" by funding the National Cancer Moonshot Initiative with the requested $680 million for the NCI.** Fulfilling these requests will ensure we can continue to transform cancer care, spur innovation and economic growth, maintain our position as the global leader in science and medical research, and most importantly, bring hope to cancer patients and their loved ones everywhere. The AACR looks forward to working with you to ensure that researchers have the resources they need to continue to deliver hope to those who are confronting this dreaded disease.

AMERICAN SOCIETY OF HEMATOLOGY
2021 L Street, NW, Suite 900, Washington, DC 20036 ph 202.776.0544 fax 202.776.0545 e-mail ASH@hematology.org

American Society of Hematology
Statement to the
House Appropriations Subcommittee on
Labor, HHS, Education, and Related Agencies

Fiscal Year 2017 Funding for the National Institutes of Health (NIH) and the Centers for Disease Control and Prevention (CDC)

April 15, 2016

The American Society of Hematology (ASH) thanks the Subcommittee for the opportunity to submit written testimony on the fiscal year (FY) 2017 Departments of Labor, Health and Human Services, and Education Appropriations bill.

ASH represents more than 15,000 clinicians and scientists committed to the study and treatment of blood and blood-related diseases. These diseases encompass malignant disorders such as leukemia, lymphoma, and myeloma; life-threatening conditions, including thrombosis and bleeding disorders; and congenital diseases such as sickle cell anemia, thalassemia, and hemophilia. In addition, hematologists have been pioneers in the fields of bone marrow transplantation, stem cell biology and regenerative medicine, gene- and immunotherapy, and the development of many drugs for the prevention and treatment of heart attacks and strokes.

Funding for Hematology Research: An Investment in the Nation's Health

Over the past 60 years, American biomedical research has led the world in probing the nature of human disease. This research has led to new medical treatments, saved innumerable lives, reduced human suffering, and spawned entire new industries. This research would not have been possible without support from the National Institutes of Health (NIH).

Funding for hematology research has been an important component of this investment in the nation's health. Much of the research that produced cures and treatments for hematologic diseases has been funded by the NIH. The study of blood and its disorders is a trans-NIH issue involving many institutes at the NIH, including the National Heart, Lung and Blood Institute (NHLBI), the National Cancer Institute (NCI), the National Institute of Diabetes, Digestive and Kidney Diseases (NIDDK), and the National Institute on Aging (NIA).

With the advances gained through an increasingly sophisticated understanding of how the blood system functions, hematologists have changed the face of medicine through their dedication to improving the lives of patients. As a result, children are routinely cured of acute lymphoblastic leukemia (ALL); more than 90 percent of patients with acute promyelocytic leukemia (APL) are cured with a drug derived from vitamin A; older patients suffering from previously lethal chronic myeloid leukemia (CML) are now effectively treated with well-tolerated pills; and patients with multiple myeloma are treated with new classes of drugs.

Hematology advances also help patients with other types of cancers, heart disease, and stroke. Even modest investments in hematology research have yielded large dividends for other

disciplines. Basic research on blood has aided physicians who treat patients with heart disease, strokes, end-stage renal disease, cancer, and AIDS. Blood thinners effectively treat or prevent blood clots, pulmonary embolism, and strokes. Death rates from heart attacks are reduced by new forms of anticoagulation drugs.

Future Promise

The era of precision medicine has arrived. The field of hematology has experienced a recent surge in progress thanks to novel technologies, mechanistic insights, and cutting-edge therapeutic strategies that have driven significant and meaningful advances in the quality of care. Insights into new genetic and biologic markers can be used to understand what causes a disease, the risk factors that predispose to disease, and how patients will respond to a particular treatment. These foundational insights are reframing modern research with the continued goal of improving outcomes and discovering cures for the most challenging hematologic diseases.

Translating these new discoveries and technologies into personalized patient care offers the possibility of better survival, less toxicity, disease prevention, improved quality of life, and lower health-care costs. Yet today, a number of specific and critically important research questions must be answered to gain the insights that will launch the field into the next generation of care for hematologic conditions. A wide variety of blood-related diseases – from malignancies such as lymphoma and leukemia, to non-malignant diseases including hemoglobinopathies such as sickle cell disease and thalassemia – continue to be associated with significant morbidity and mortality and demand attention to reduce their burden and improve the quality of care worldwide.

FY 2017 Requests

NIH Funding

ASH thanks Congress for the robust bipartisan support that resulted in the welcome and much needed funding increase for the NIH that Congress provided in the FY 2016 Consolidated Appropriations Act. ASH supports the Ad Hoc Group for Medical Research recommendation that NIH receive at least $34.5 billion in FY 2017 as the next step toward a multi-year increase in our nation's investment in medical research. If the nation is to continue to accelerate the development of life-changing cures, pioneering treatments, and innovative prevention strategies, it is essential to sustain predictable increases in the NIH budget. Trials to find new therapies and cures for millions of Americans with blood cancers, bleeding disorders, clotting problems, and genetic diseases are just a few of the important projects that could be delayed unless NIH continues to receive predictable and sustained funding. This requested $2.4 billion increase represents 5 percent real growth above the projected rate of biomedical inflation, and will help ensure that NIH-funded research can continue to improve our nation's health and enhance our competitiveness in today's global information and innovation-based economy.

Additionally, the Society strongly supports the Administration's proposed Moonshot Initiative, which seeks to accelerate progress across all cancers by supporting research in cancer prevention and vaccine development, early detection, immunotherapy and combination therapy, genomic analysis, data sharing, and pediatric cancer.

Centers for Disease Control and Prevention (CDC) Public Health Response for Blood Disorders
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. Blood disorders – such as sickle cell disease, anemia, blood clots, and hemophilia – are a serious public health problem and affect millions of people each year in the United States, cutting across the boundaries of age, race, sex, and socioeconomic status. Men, women, and children of all backgrounds live with the complications associated with these conditions, many of which are painful and potentially life-threatening.

CDC is uniquely positioned to reduce the public health burden resulting from blood disorders by contributing to a better understanding of these conditions and their complications; ensuring that prevention programs are developed, implemented, and evaluated; ensuring that information is accessible to consumers and health care providers; and encouraging action to improve the quality of life for people living with or affected by these conditions. The Society is concerned that the Division of Blood Disorders was cut by over $4 million in the Consolidated Appropriations Act of 2014. ASH respectfully requests that the Committee restore funding for the Division of Blood Disorders, by including increased funding to the public health approach to blood disorders account to enable CDC to meet growing needs for programs to address sickle cell disease and deep vein thrombosis/ pulmonary embolism (DVT/PE). This funding will allow CDC to improve health outcomes and limit complications to those who are risk or currently have bleeding and clotting disorders, by promoting a comprehensive care model; identifying and evaluating effective prevention strategies; and increasing public and healthcare provider awareness.

Additional Activities
In FY 2017, ASH also urges the Subcommittee to recognize the following activities impacting hematology:

- **Centers for Disease Control and Prevention, National Center on Birth Defects and Developmental Disabilities**
  - ***Report Language:***
    Sickle Cell Disease – The Committee believes more can be done to educate patients and medical providers about sickle cell disease (SCD) and sickle cell trait (SCT). It is especially important that individuals know their sickle cell status, the potential for medical complications, and the implications when making reproductive choices and that providers be informed of the current recommendations (best practices) for providing medical care to individuals with SCD/SCT. The Committee asks that the Center's Blood Disorders Division provide a plan on how to carry out a public health awareness and education campaign to meet these goals.

  - ***Background:***
    Sickle cell disease is the most common inherited red blood cell disorder in the United States, affecting approximately 100,000 Americans (mostly but not exclusively of African ancestry). SCD causes the production of abnormal hemoglobin, which can get stuck and block blood flow, causing pain and infections. Complications of sickle cell anemia include stroke, acute chest syndrome, organ damage, other disabilities, and in some cases premature death. Most SCD patients can expect to

live into adulthood, but the cost of care and the burden of pain, end-organ injury, and premature death remain high.

- **Centers for Medicare and Medicaid Services, Program Management**
  - ***Report Language:***
    Sickle Cell Disease – The Committee encourages CMS working through the Center for Medicare and Medicaid Innovation to explore with the interested provider and patient organizations, the development of model programs to provide integrated comprehensive care for adults with sickle cell disease (SCD). With an estimated 50% of the SCD population served under Medicaid and another 25% on Medicare, CMS has every incentive to assure that individuals with SCD are able to access specialized high quality services. Consideration should be given to funding of care coordinators/case managers for this population with incentives to reduce hospital admissions/ readmissions and emergency department visits.

  - ***Background:***
    Sickle cell disease is the most common inherited red blood cell disorder in the United States, affecting approximately 100,000 Americans (mostly but not exclusively of African ancestry). SCD causes the production of abnormal hemoglobin, which can get stuck and block blood flow, causing pain and infections. Complications of sickle cell anemia include stroke, acute chest syndrome, organ damage, other disabilities, and in some cases premature death. According to the Agency for Healthcare Research and Quality (AHRQ) Healthcare Cost and Utilization Project – 2012, Sickle cell disease was the 5th most common discharge diagnosis for hospital "super users" for Medicaid patients under 64 and patients with SCD are high utilizers of emergency room services. Most SCD patients can expect to live into adulthood, but the cost of care and the burden of pain, end-organ injury, and premature death remain high.

Thank you again for the opportunity to submit testimony. Please contact Tracy Roades, ASH Legislative Advocacy Manager, at 202-776-0544 or troades@hematology.org, if you have any questions or need further information concerning hematology research or ASH's FY 2017 requests.

CONEG
COALITION OF NORTHEASTERN GOVERNORS

Statement of the Coalition of Northeastern Governors to the Subcommittee on Labor, Health and Human Services, Education, and Related Agencies Committee on Appropriations United States House of Representatives Regarding FY2017 Appropriations for the Low Income Home Energy Assistance Program (LIHEAP) Department of Health and Human Services April 15, 2016

The Coalition of Northeastern Governors (CONEG) is pleased to share with the Subcommittee on Labor, HHS, Education, and Related Agencies this testimony for the hearing record regarding FY2017 appropriations for the Low Income Home Energy Assistance Program (LIHEAP). The Governors recognize the challenging fiscal decisions facing Congress this year, and deeply appreciate the Subcommittee's long-standing support for this vital program. They also recognize the struggles that millions of the nation's low-income households face to safely heat and cool their homes. Therefore, they urge the Subcommittee to provide no less than $4.7 billion in regular LIHEAP block grant funding in FY2017. They also urge the Subcommittee to provide these funds in a manner consistent with the LIHEAP statutory objective of assisting those households with the highest energy burden; and to ensure that the full appropriated funds are released to the states in a timely manner.

LIHEAP provides a vital lifeline to the most vulnerable households – the elderly, disabled and families with children under the age of five. Moreover, approximately 20 percent of LIHEAP households have at least one member who served this country in the military. Many of these LIHEAP-eligible households live on fixed, very modest incomes: approximately $24,000 annually for a two-person household and $36,450 for four persons. Even though the average cost of heating a home (for all fuel types) slightly decreased in the past year from $880 to a projected $779 for the just-ended heating season, many LIHEAP households across the country still struggle to pay their heating bills.

Households in the Northeast face some of the nation's highest home heating bills due to the extended winter heating season and heating fuel prices that typically exceed national averages regardless of the fuel used. Approximately 30 percent of households in the northeast states rely upon delivered fuels, such as home heating oil or propane. For these delivered-fuel households, the average cost for heating their home – $1,282 for home heating oil; $1,368 for propane – is much higher than the national average cost to heat a home. Low-income households that are dependent on delivered fuels face additional challenges in managing their home-heating costs. Compared to homes heating with natural gas or electricity, these delivered-fuel households are less likely to have the option of payment plans, access to utility assistance programs, and the

400 North Capitol Street, N.W. • Suite 382 • Washington, DC 20001 • (202) 624-8450 • Fax (202) 624-8463
E-mail coneg@sso.org • www.coneg.org
Printed on recycled paper

protection of utility service shut-off moratoria during the heating season. LIHEAP funds are particularly critical for these households, as the typical LIHEAP benefit covers, on average, one-third of the total home heating bill for the season. If LIHEAP funds are not available to these households, the fuel delivery truck simply does not come.

Reducing home energy costs also presents unique challenges to northeast states. The region has some of the country's oldest homes, many of which have structural issues that make them ineligible for weatherization assistance. Low-income families are more likely to rent than to own a home and therefore have less ability or incentive to make significant energy efficiency upgrades. In addition, the cost of switching to less expensive heating fuels is often prohibitive and is simply not possible in rural and metropolitan areas not served by natural gas infrastructure.

State LIHEAP programs continue to develop innovate ways to stretch scarce LIHEAP dollars while providing a meaningful benefit to those households with the greatest need. States have negotiated with fuel vendors to receive discounts on delivered fuels and have worked with utilities to develop payment plans to reduce the possibility of service shut-offs once the moratoria end. Even with these cost-efficient changes, in recent years states have had to take actions such as tightening program eligibility, closing the program early, and reducing benefit levels.

In summary, the CONEG Governors appreciate the Subcommittee's continued support for LIHEAP. They urge you to fund the core block grant program at the level of no less than $4.7 billion in FY2017, and to provide the funds in a manner that is consistent with the LIHEAP statutory objective of addressing those households with the highest energy burden while also ensuring that the full appropriated funds are released to the states in a timely manner.

The Freedom Center 2016 Appropriations Testimony

Jamey George

Executive Director

The Freedom Center, Inc.

April 15, 2016

Prepared for:

House Appropriations Subcommittee on Labor, Health and Human Services, Education, and Related Agencies

My name is Jamey George, and I am the Executive Director of The Freedom Center. The Freedom Center is a center for independent living located in Frederick, MD. We serve people with disabilities who reside in Frederick and Carroll Counties in the State of Maryland. Our mission is to provide services and supports to empower people with disabilities to lead self-directed, independent, and productive lives in a barrier-free community. To do so, we strive to remove physical and attitudinal barriers in the community so people with disabilities can choose to live in the most integrated setting within the community of their choice. We work with a cross-disability population with no age limits. Our services are self-directed by people with disabilities who receive assistance from our staff who are also people with disabilities. The Freedom Center's Board of Directors is largely comprised of people with disabilities. I would like to begin by thanking you for your commitment to enabling people with disabilities to participate fully in their communities by investing in the Independent Living Program. I am writing to support the National Council on Independent Living's request for Congress to reaffirm your commitment to the more than 57 million Americans disabilities by increasing funding in the HHS appropriations for Centers for Independent Living (CILs). I am asking that you increase funding by $200 million, for a total of $301 million for the Independent Living line item in FY 2017.

CILs are cross-disability, non-residential, community-based, nonprofit organizations that are designed and operated by individuals with disabilities. CILs are unique in that they are directly governed and staffed by people with all types of disabilities, including people with mental, physical, sensory, cognitive, and developmental disabilities. Each of the 365 federally funded centers provides five core services: information and referral, individual and systems advocacy, peer support, independent living skills training, and transition services, which were added with the passage of the Workforce Innovation and Opportunity Act (WIOA). From 2012-2014, CILs provided the core services to nearly 5 million people with disabilities, and provided additional services such as housing assistance, transportation, personal care attendants, and employment

services to hundreds of thousands of individuals. During this same period, prior to transition being added as a core service, CILs transitioned 13,030 people with disabilities from nursing homes and other institutions into the community.

In FY 2015, The Freedom Center, alone, provided services and support to 534 active consumers and 2,600 I and R callers for a total of 3,134 people with disabilities, family members, friends, and agencies. Services were provided to 49 people with cognitive disabilities, 102 people with mental/emotional disabilities, 196 people with physical disabilities, 53 people with hearing impairments, 15 people with visual impairments, 21people with multiple disabilities, and 98 people with other disabilities that are not categorically listed in our annual reports and these include disabilities such as acquired illnesses. The types of services that are requested include advocacy/legal services, assistive technology, communication services, counseling and related services, family services, housing, home modifications, and shelter services, IL skills training and life skills training, mental restoration services, mobility training, peer counseling services, personal assistance services, recreational services, transportation services, youth/transition services, vocational services, and other services not listed. Beyond our five core services, we provided assistance to people requesting help with education, accessibility, nursing home transition, employment, transportation, Social Security benefits and benefits planning, information access, community/social participation, health care services, housing, etc. In this year, we were able to provide assistance to people with disabilities who were residing in nursing homes to relocate to the community. In the past year, we transitioned 12 people to the community. In the last year and a half, we have become an Employment Network which is allowing us to provide services that will help people find jobs and join the workforce to become taxpaying citizens which is the ultimate in successfully living independently. We are a small CIL with 7 employees. We are only one center for independent living out of 365 federally funded centers nationwide.

Transition services were added as a fifth core service with the 2014 reauthorization of the Rehabilitation Act within the Workforce Innovation and Opportunity Act. Transition services include the transition of individuals with significant disabilities from nursing homes and other institutions to home and community-based residences with appropriate supports and services, assistance to individuals with significant disabilities at risk of entering institutions to remain in the community, and the transition of youth with significant disabilities to postsecondary life. This core service is vital to achieving full participation for people with disabilities.

Every day, CILs are fighting to ensure that people with disabilities gain and maintain control over our own lives. We know that this cannot occur when people reside in institutional settings.

Opponents of deinstitutionalization say that allowing people with disabilities to live in the community will result in harm. We know that the 13,030 people with disabilities who CILs successfully transitioned out of nursing homes and institutions from 2012-2014 prove otherwise. Additionally, when services are delivered in an individual's home, the result is a tremendous cost savings to Medicaid, Medicare, and states. Community-based services enable people with disabilities to become less reliant on long-term government supports, and they are significantly less expensive than nursing home placements. We are grateful that Congress demonstrated their understanding and support for community-based services when WIOA was passed and transition was added as a fifth core service.

Since transition services were added as a core service, the need for funding is critical. Moreover, CILs need additional funding to restore the devastating cuts to the Independent Living program, make up for inflation costs, and address the increased demand for independent living services. In 2016, the Independent Living Program is receiving $2.5 million less in funding than it was in 2010. It is simply not possible to meet the increasing demand for services and effectively provide transition services without additional funding. Increased funding should be reinvested from the billions currently spent to keep people with disabilities in costly Medicaid nursing homes and institutions and out of mainstream society.

Centers for Independent Living play a crucial role in the lives of people with disabilities, and work tirelessly to ensure that people with disabilities have a real choice in where and how they live, work, and participate in the community. Additionally, CILs are an excellent service and a bargain for America, keeping people engaged with their communities and saving taxpayer money. NCIL is dedicated to increasing the availability of the invaluable and extremely cost-effective services CILs provide, and they have submitted written testimony with a similar request. I strongly support NCIL's testimony.

Robert Blancato
National Coordinator
Elder Justice Coalition

Chairman Cole, Ranking Member DeLauro;

On behalf of the bipartisan Elder Justice Coalition and its 3,000 members, we thank you for the opportunity to offer testimony in support of $25 million in funding for the Elder Justice Act within the Department of Health and Human Services' Administration for Community Living, as well as for maintaining funding for the Social Services Block Grant.

Our topic must always be a bipartisan issue: preventing elder abuse, neglect and exploitation. We ask this Subcommittee to provide this funding in a bipartisan fashion as part of the solution to the national disgrace of elder abuse.

According to the Department of Justice, there are more than six million victims of elder abuse per year; roughly one of every ten persons over 60 will end up a victim of elder abuse. However, a New York State study found for every elder abuse case known to agencies, twenty-four were unreported. Victims of elder financial abuse lose at least $2.9 billion per year, which can include entire life savings. A 2015 study published by True Link Financial found that the problem of financial exploitation may be as great as $36 billion per year. One-half of those with dementia will fall victim to elder abuse, neglect and/or exploitation. In short, the situation is dire.

The Elder Justice Act, passed in 2010, would address these problems. The Act, if funded, would strengthen the State Long-Term Care Ombudsman Program. It would provide for the development of forensic centers to study the problem of abuse and how we can better detect abuse and potential abusers. It would also enhance and train long-term care staffing in facilities.

Funding for the Elder Justice Act has not been provided to fulfill the provisions of the Act. We are very grateful for the funding from the Appropriations Committee last year for the Act in the amount of $8 million, but the Act needs more of an investment in order to fulfill its potential. This is why we support funding for the Act at last year's proposed $25 million level.

Data collection is essential to understanding and preventing elder abuse. Other forms of crime, such as child abuse, have standardized national databases—the National Child Abuse and Neglect Data System (NCANDS) database has been in existence since 1998. This allows states to more easily discover trends and researchers to learn about perpetrators and victims. A lack of data has also hurt the elder justice community's efforts to call awareness to the problem of elder abuse and to compete effectively for resources in an era where data often drives dollars. Continuing the work started in FY 2013 with the continued funding of a National Adult Maltreatment Reporting System (NAMRS), a national Adult Protective Services (APS) data collection system, is vital for consistency in the field.

The Coalition also supports the evaluation and analysis of APS programs using an evidence-based approach and best practices. To be effective, APS programs must have consistency and

high quality nationally. Elder abuse happens in all states and congressional districts, and in some cases, elder abuse happens across county and state lines. Thus, having uniform best practices is key to ensuring that victims receive uniform services.

Research in the elder abuse field, like data collection, is desperately needed. Money has never been specifically appropriated for research; the limited resources that the field has go straight into assisting victims. However, victims can be more appropriately—and cost-effectively—assisted if they are identified early via effective screening. A great deal of trauma can be prevented with effective screening. Thus, research into how to screen accurately is exceedingly important.

This increased investment of $25 million would mean that current federal and state resources could be used more effectively while also responding to elder abuse systematically. For these reasons, as well as the potential of lowering rates of future victimization, the investment would provide a solid return on investment.

This is an investment because, according to the National Center on Elder Abuse, the direct medical costs associated with elder abuse now exceed $5 billion annually. Since these victims are older adults, Medicare and Medicaid bear the bulk of these costs. Other federal programs may end up paying for elder abuse victims, including income support programs, because financial abuse victims who were once self-supporting may lose everything in one scam. We can save money for the federal government if we make this relatively small investment today.

We also support maintaining, if not increasing, the amount of money available for Social Services Block Grant programs, which in addition to providing APS funding, also provides important funding for supportive services available to elder abuse victims. APS is primarily funded through optional state distributions from their Social Services Block Grant allotment; only 37 states provide any additional federal funding for their federal APS programs.

Since the Elder Justice Act has many more important provisions that are not funded in this proposal, please view this $25 million as a floor to build on, and not a ceiling. We look forward to working with you to ensure that this elder justice appropriation provides our nation with the best possible return on investment and outcomes.

Thank you for your past and future support.

FASEB
Federation of American Societies for Experimental Biology

Representing 125,000 Researchers

301.634.7000
www.faseb.org

9650 Rockville Pike
Bethesda, MD 20814

Contact:
Jennifer Zeitzer
Director of Legislative Relations
Federation of American Societies for Experimental Biology (FASEB)

Testimony of the

Federation of American Societies for Experimental Biology

Prepared for the

House Committee on Appropriations
Subcommittee on Labor, Health and Human Services, Education, and Related Agencies
Representative Tom Cole, Chairman
Representative Rosa DeLauro, Ranking Member

On

FY 2017 Appropriations for the National Institutes of Health

The Federation of American Societies for Experimental Biology (FASEB) respectfully requests a minimum of $35 billion in fiscal year (FY) 2017 for the National Institutes of Health (NIH) within the Department of Health and Human Services.

FASEB, a federation of 30 scientific societies, represents 125,000 life scientists and engineers, making it the largest coalition of biomedical research associations in the United States. Our mission is to advance health and welfare by promoting progress and education in biological and biomedical sciences.

The National Institutes of Health (NIH) is the largest source of funding for biomedical research in the world. Approximately 84 percent of NIH funds are distributed through more than 60,000 research and training grants to over 300,000 scientists employed at universities, medical schools, and other research institutions in all 50 states and nearly every congressional district. To date, 148 Nobel Laureates were funded by NIH over the course of their careers, including the 2015 winners of the Nobel Prizes in Chemistry and Economics.

NIH has produced an outstanding legacy of discoveries that have improved health, saved lives, generated new knowledge and trained generations of scientists. Investment in biomedical research funded by NIH has supported discoveries that reduced deaths from cancer and rates of

disability due to stroke, heart disease, Hepatitis B, and osteoporotic fractures, prolonging life and reducing suffering. Many of these advances arose from scientists investigating questions designed to explain fundamental molecular, cellular, and biological mechanisms in non-human and even non-mammalian study systems. Research supported by NIH has expanded our understanding of the molecular roots of various cancers and led to important insights into how microbial communities affect a range of chronic diseases including diabetes. Investigators funded by NIH have also made critical advances in genomics and proteomics, leading to the discovery of more than a thousand risk factors for various diseases. In addition, entirely new global industries and innovative technologies have been created, stimulating our nation's economic growth.

New scientific breakthroughs such as advanced cellular imaging are being used to view the inner workings of living tissues in greater detail and with more accuracy. Basic research supported by NIH also fuels advances in our understanding of infectious diseases, improving the lives of millions of people worldwide.

NIH-funded research is continuing to produce the insights that are needed for tomorrow's improvements in health and clinical care. Recent discoveries include:

- **Vaccines: Weapons in the Fight Against Disease**: Vaccines are powerful weapons in the fight against disease. They have averted more than 100 million cases of disease in the United States and continue to prevent 2.5 million deaths globally every year. Using advances in immunology and molecular genetics, scientists continue to develop new kinds of vaccines that hold promise for better efficacy by eliciting immune responses similar to those that occur naturally upon entry of an intruding microbe. For example, researchers at the National Institute of Allergy and Infectious Diseases have co-developed a vaccine aimed at preventing the devastating disease, Ebola. This vaccine was shown to be safe and induced an immune response in human trials, and has moved on for further testing in West African populations affected by this disease.[1]

- **The Microbiome: Our Personal Ecosystem**: For more than three hundred years, scientists have observed, identified, and implicated individual microorganisms in specific diseases. More recently, with a convergence of scientific disciplines, an explosion in technical capabilities, and revolutionary new ways of thinking, scientists are exploring the organisms with which we share our bodies. Understanding of the microorganisms that live in and on us – our microbiome – will provide insights into how they can influence human health and disease. NIH-funded researchers at the Washington University in St. Louis recently discovered that babies can be populated with their mother's microbes *in utero* in contrast to the commonly held belief that the newborns' microbiomes were not established until after birth. This finding can help scientists further understand how a mother's microbial status can impact the long-term health of the child.[2]

---

[1] http://www.faseb.org/Portals/2/PDFs/opa/2015/10.23.15%20FASEB-BreakthroughsInBioscience-Vaccines%20-WEB.pdf

[2] http://www.faseb.org/Portals/2/PDFs/opa/2015/Breakthroughs%20In%20Bioscience%20Human%20Microbiome.pdf

- **Organs-on-a-Chip: Tools for Drug Discovery and Study of Disease**: This emerging technology of organs-on-a-chip allows scientists to watch the cascade of events that takes place in organs in response to drugs or during disease. These 3-D biochips contain living human cells from an organ or tissue that can mimic the mechanical motion of internal organs and structures. The artery-on-a-chip developed by NIH-funded researchers at the University of California Davis provides an unprecedented view of how atherosclerosis develops in coronary arteries and how activation of white blood cells related to inflammation influences the risk of heart problems. This improved understanding could lead to novel anti-inflammation therapies and, eventually, to new tools to predict, monitor, and treat atherosclerosis.[3]

- **Nanoparticles: A Targeted Approach to Medicine**: Nanomedicine is beginning to change the way scientists and physicians diagnose and treat disease. Unlike conventional therapies, these tiny particles – 1,000 times smaller than the diameter of a human hair – can seek out diseased tissue and access hard to reach places in the body. NIH-funded researchers at Clemson University designed nanoparticles that can identify sites of vascular injury in an animal model of cardiovascular disease. Specialized imaging showed that the nanoparticles only adhere to damaged blood vessels, while avoiding healthy tissue. In the future, researchers hope to modify these nanoparticles to deliver drugs to the sites of vascular injury and repair the damaged tissue.[4]

- **Precision Medicine: Fine-Tuning Disease Diagnosis and Treatment**: Precision medicine is a medical paradigm offering customizable medicine based on one's genes that can be used to prevent, diagnose, and treat disease. Innovations in precision medicine come from technological advances that make it both feasible and affordable to decipher a person's complete genetic make-up. This new genetic landscape is already causing a paradigm shift in how cancer is diagnosed and treated, with molecular diagnosis adding to or replacing traditional pathological diagnosis based on microscopic features of tumors. For example, a group of scientists working with NIH's Cancer Genome Atlas analyzed the DNA profiles of over 300 malignant melanoma cancer tissues, the results of which unveiled a set of 13 genetic mutations that can drive the cancer's growth and will enable physicians to treat each patient with drugs targeted to the specific mutation.[5]

Sustained Funding Is Critical to Continue Progress and Take Advantage of New Scientific Opportunities

NIH needs sustained increases in funding to continue the research that paves the way to new therapies and to respond to urgent public health needs as they arise. We can now address new questions about biology and behavior that were previously thought to be unanswerable. New scientific breakthroughs such as advanced cellular imaging to view the inner workings of living tissues in greater detail and with more accuracy will be possible. Increasing collaborations between researchers from different fields of science are facilitating ideas for better strategies to prevent, diagnose, and treat a variety of diseases. As the FY 2016-2020 NIH-wide strategic plan

[3] http://www.faseb.org/Portals/2/PDFs/opa/2015/FASEB-HorizonsInBioscience-OrgansOnAChip-Web.pdf
[4] http://www.faseb.org/Portals/2/PDFs/opa/2015/nanoparticles%20horizons%20article.pdf
[5] http://www.faseb.org/Portals/2/PDFs/opa/2014/Individualized%20Medicine%20Breakthroughs.pdf

notes, "a strengthened and sustained commitment to NIH-supported research is critical because delays in scientific progress can have a dire impact on the health of individuals and the communities in which they live, as well as our nation's overall public health and wellbeing"[6].

The FY 2017 appropriation for NIH must build on and expand the agency's capacity to fund research in order to improve quality of life, address the rising costs of caring for our aging population, and reduce illness and disability. In July 2015, the House of Representatives recognized the challenges facing the biomedical research enterprise and passed the 21st Century Cures Act (HR 6). The bipartisan bill, which was supported by more than 300 members of Congress, recommended that NIH receive an additional $3.0 billion per year in discretionary and mandatory funding in FY 2016-2018. Related legislation is currently being developed in the U.S Senate.

Congress took a much-needed first step towards fulfilling the goals of the 21st Century Cures Act by providing a two billion dollar increase for NIH in FY 2016. We encourage Congress to continue the funding trajectory envisioned in this legislation as there are excellent proposals for outstanding research that are unable to be funded with current budget levels. When the American Recovery and Reinvestment Act enabled NIH institutes to support additional R01 grants, analyses demonstrated that these added grants were as productive on a per-dollar basis as those that were funded with the regular appropriation.[7] An increase of $3.0 billion for FY 2017 levels would enable NIH to fund more R01 grants while still providing much needed increases to other parts of the portfolio. If the percentage of the new funding used for R01 grants is the same as in prior years, NIH could fund more than 2,200 additional R01 grants. This would bring the total number of R01 grants back to the level supported in FY 2003 (7,400), the highest in the agency's recent history.

Sustained increases in funding are necessary for the NIH to continue to train and support the next generation of researchers. For example, increased funding can also be used to raise the stipends for postdocs and other trainees as recommended by FASEB.[8] Additional funding can be used to supplement research and training grants by five percent as a first step toward a multi-year commitment to reaching the target salary recommendations from the National Academy of Sciences[9], the National Postdoctoral Association[10], and FASEB.[11]

To continue to grow the nation's capacity for biomedical research, and as a first installment of a multi-year program of sustainable increases, FASEB recommends at least $35.0 billion for NIH in FY 2017.

---

[6] *NIH-Wide Strategic Plan, Fiscal Years 2016–2020: Turning Discovery Into Health.* http://www.nih.gov/sites/default/files/about-nih/strategic-plan-fy2016-2020-508.pdf

[7] Narasimhan S. Danthi, Colin O. Wu, Donna M. DiMichele, W. Keith Hoots, and Michael S. Lauer, "Citation Impact of NHLBI R01 Grants Funded Through the American Recovery and Reinvestment Act as Compared to R01 Grants Funded Through the Standard Payline," *Circulation Research*, 2015; 116:784-788

[8] Federation of American Societies for Experimental Biology, *Sustaining Discovery*, Bethesda, MD: FASEB.

[9] National Academies of Science. (2014). *The Postdoctoral Experience Revisited.* Washington, D.C.: The National Academies Press.

[10] National Postdoctoral Association website https://c.ymcdn.com/sites/npamembers.site-ym.com/resource/resmgr/Docs/NPA_Overtime_Response_-_08.2.pdf

[11] In 2011, FASEB recommended a stipend level of $45,000 with subsequent cost of living increases.

STATEMENT BY AMERICAN HEART ASSOCIATION
MARK CREAGER, M.D., PRESIDENT
202-785-7900; claudia.louis@heart.org; 1150 Connecticut Ave, NW, DC 20036

FY 2017 LABOR-HHS-EDUCATION APPROPRIATIONS: NIH: $34.5 BILLION & CDC: $7.8 BILLION

On behalf of our 30 million volunteers and supporters, the American Heart Association commends Congress for providing a major FY 2016 boost for the National Institutes of Health and for the Centers for Disease Control and Prevention's heart disease and stroke programs, and for placing an enhanced focus on disease burden. The association strongly believes that fact-based disease burden measures should be a guide when Congress and policymakers allocate research and prevention funding and set program priorities for NIH and CDC for FY 2017.

Measuring how much actual harm and suffering a specific disease exacts upon our society—through numbers of deaths, disability and associated medical costs—is an invaluable tool in making better informed funding decisions. By aligning resources to these analytics, we can have the greatest impact in improving the health and well-being of tens of millions of Americans while reducing health care costs.

Sadly, cardiovascular disease (CVD), including heart disease and stroke, rank at the top of the disease burden list. Today, nearly 86 million U.S. adults suffer from some form of CVD and it is projected that by the year 2030, nearly 44% of U.S. adults will live with CVD at a cost over $1 trillion annually. For example, stroke deaths have fallen, but there has been little stroke risk reduction. So, more people are living with permanent cognitive or physical disability post stroke.

Yet inexplicably, research and prevention remain disproportionately underfunded when compared to the crushing burden CVD inflicts upon our nation's physical and economic health – one that we all shoulder. Despite a whopping $30-to-$1 return on investment, NIH funds a meager 4% of its budget on heart research, a mere 1% on stroke research, and a scant 2% on other CVD research. This glaring disparity must be addressed – and addressed soon – beginning with the FY 2017 appropriations process.

AHA and its millions of volunteers want to work with Congress to protect, preserve, and restore funding for NIH-funded research. We want to build healthier lives free of cardiovascular diseases and stroke. Leveraging disease burden measures is crucial to achieving that goal

FUNDING RECOMMENDATIONS: INVESTING IN THE HEALTH OF OUR NATION

Despite the very real threat CVD poses to our Nation's health and economy, research that could ultimately develop a cure goes unfunded. Inadequate and unreliable funding are two of the most intractable problems we face. However, the American Heart Association's funding recommendations are both fiscally responsible and reflect the burden CVD imposes.

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

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

In addition to improving health, NIH produces a solid return on investment. In 2014, NIH supported more than 400,000 U.S. jobs and over $58 billion in economic activity. Every $1 in NIH funding created $2 in economic activity in 2007. Yet, due to inadequate resources since 2003, NIH has lost more than 19% of its purchasing power. Ironically, this decline has occurred at a time of unprecedented scientific opportunity as other countries, like China, wisely increased investment in science—some by double digits. These cuts have disheartened early U.S. career scientists who may decide against pursuing careers in research unless Congress acts.

***American Heart Association Advocates*:** We urge Congress to appropriate $34.5 billion for NIH to continue to restore its purchasing power and advance cardiovascular disease research.

Enhance Funding for NIH Heart and Stroke Research: A Proven and Wise Investment

NIH research plays a vital role in cutting CVD death rates. Today, scientists are closer to discoveries that could result in revolutionary treatments and even cures. In addition to saving lives, NIH studies can produce substantial cost savings. For example, investments in the NIH Women's Health Initiative postmenopausal estrogen plus progestin trial generated an economic return of $140 for every $1 invested and led to 76,000 fewer cases of cardiovascular disease. The first NIH tPA drug trial led to a 10-year net $6.47 billion cut in stroke care costs.

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

Much of the decline in CVD death rates is a result of NHLBI research. However, current funding is not commensurate with CVD disease burden, nor does it allow us to capitalize on investments that have led to major advances. For example, a landmark clinical trial showed setting a systolic blood pressure goal of 120 mm Hg in adults over age 50 cut cardiovascular events (heart attack,

heart failure, and stroke) by 25% and reduced the risk of death by 27%, compared to the standard treatment target of 140 mm Hg.

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

Stroke continues to place an immense burden on our society and economy. An estimated 795,000 Americans will suffer a stroke this year, and nearly 129,000 will die. Many of the 7 million survivors face grave physical, mental, and emotional distress. In addition, stroke costs an estimated $33 billion in medical expenses and lost productivity each year and a study projects that direct costs of stroke will triple between 2012 and 2030.

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

American Heart Association Advocates: We recommend that NHLBI be funded at $3.4 billion and NINDS at $1.8 billion.

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

Prevention is the best way to protect against the ravages of CVD. Yet, proven efforts are not fully executed due to insufficient resources. In addition to funding research and evaluation and developing

a surveillance system, the Division for Heart Disease and Stroke Prevention directs Sodium Reduction in Communities and the Paul Coverdell National Acute Stroke programs. DHDSP and the CMS coordinate the Million Hearts™ initiative to prevent 1 million heart attacks and strokes by 2017. DHDSP also runs WISEWOMAN, serving uninsured and under-insured, low-income women ages 40 to 64 through preventive health services, referrals to local health care, and tailored lifestyle plans to foster lasting behavioral change.

American Heart Association Advocates: We join the CDC Coalition in asking for $7.8 billion for the agency. AHA requests $160.037 million for the DHDSP to intensify work on the State Public Health Actions and on the State and Local Public Health Actions To Prevent Obesity, Diabetes, and Heart Disease, and Stroke; and $37 million for WISEWOMAN for expansion to additional and currently-funded states. We ask for $5 million for Million Hearts™ to support enhanced ways to implement ABCS: aspirin when appropriate, blood pressure control, cholesterol management, and smoking cessation; and activities to increase the use of cardiac rehabilitation. Although cardiac rehabilitation can reduce cardiovascular deaths by nearly 30%, and re-hospitalizations by more than 30%, less than 20% of eligible patients participate.

CONCLUSION

Cardiovascular disease, including heart disease and stroke, inflicts the highest disease burden on Americans. Our budgetary recommendations for NIH and CDC will save lives and reduce health care costs. We respectfully ask Congress to enact our recommendations that are a wise investment for the long-term health and economic well-being of our Nation.

Testimony of
Dr. Tom Maniatis, PhD
Director
Columbia Precision Medicine Initiative (CPMI)
Columbia University
New York City, New York
Before the
Subcommittee on Labor, Health and Human Services, and Education
Committee on Appropriations
House of Representatives
In support of FY 2017 Appropriations for the National Institutes of Health
April 15, 2016

On behalf of my colleagues at Columbia University, I would like to thank this Subcommittee and the rest of your Congressional colleagues for the long standing support this Subcommittee has provided to this nation's biomedical research enterprise. Your support of the National Institutes of Health (NIH) and other research agencies is vital to the long term health of this Nation.

I am very pleased to submit this testimony which recommends funding the NIH in FY 2017 at a level of $34.5 billion. The FY 2017 appropriation for NIH must build on and expand the agency's capacity to fund research in order to improve quality of life, address the rising costs of caring for our aging population, and reduce illness and disability.

The National Institutes of Health (NIH) is the largest source of funding for biomedical research in the world. More than eighty-three percent of NIH funds are distributed through competitive grants to over 300,000 scientists employed at universities, medical schools, and other research institutions in all 50 states and nearly every congressional district. To date, 145 Nobel Laureates were funded by NIH over the course of their careers, including the 2014 winner of the Nobel Prize in Chemistry. My own research has been supported almost entirely by NIH grants over a period of nearly 40 years. NIH has produced an outstanding legacy of discoveries that have improved health, saved lives, and generated new knowledge. Many of these advances arose from scientists investigating questions designed to explain fundamental molecular, cellular, and biological mechanisms. Research supported by NIH has also expanded our understanding of the molecular roots of various cancers and led to important insights into how microbial communities affect a range of chronic diseases including obesity and diabetes. In addition, research supported by NIH led to the development of innovative technologies and created entirely new global industries that are a critical component of our nation's economic growth. Investment in biomedical research funded by NIH has supported discoveries that lowered death and disability from polio, heart disease, and cancer, prolonging life and reducing suffering. New scientific breakthroughs have given us the opportunity to dramatically accelerate desperately needed progress on therapies for thousands of diseases and conditions.

One example of the importance of NIH funding is the developing Precision Medicine Initiative which is aimed at tailoring medical care to the individual patient. The Precision Medicine Initiative will pioneer a new model of patient-powered research that promises to accelerate biomedical discoveries and provide clinicians with new tools, knowledge, and therapies to select which treatments will work best for which patients.

Most medical treatments have been designed for the "average patient." As such treatments can be very successful for some patients but not for others. This is changing with the emergence of precision medicine that takes into account individual differences in people's genes, environments, and lifestyles. Precision medicine gives clinicians tools to better understand the complex mechanisms underlying a patient's health, disease, or condition, and to better predict which treatments will be most effective.

Advances in precision medicine have already led to powerful new discoveries and several new treatments that are tailored to specific characteristics of individuals, such as a person's genetic makeup, or the genetic profile of an individual's tumor. This is leading to a transformation in the way we can treat diseases such as cancer. Patients with breast, lung, and colorectal cancers, as well as melanomas and leukemias, for instance, routinely undergo molecular testing as part of patient care, enabling physicians to select treatments that improve chances of survival and reduce exposure to adverse effects.

Translating initial successes to a larger scale will require a coordinated and sustained national effort. Through collaborative public and private efforts, the Precision Medicine Initiative (PMI) will leverage advances in genomics, emerging methods for managing and analyzing large data sets while protecting privacy, and health information technology to accelerate biomedical discoveries. The Initiative will also engage a million or more Americans to volunteer to contribute their health data to improve health outcomes, fuel the development of new treatments, and catalyze a new era of data-based and mote precise medical treatment.

A key feature of the PMI is to build a large research cohort that will provide the platform for expanding our knowledge of precision medicine approaches and that will benefit the nation for many years to come. In March 2015, NIH Director, Dr. Francis Collins formed the PMI Working Group of the Advisory Committee to the NIH Director to develop a plan for creating and managing such a research cohort. In September 2015, this working group released its report which identified a number of high value scientific opportunities including:

- Development of quantitative estimates or risk for a range of diseases by integrating environmental exposures, genetic factors, and gene-environment interactions;
- Identification of determinants of individual variation in efficacy and safety of commonly used therapeutics;
- Discovery of biomarkers that identify people with increased or decreased risk of developing common diseases;
- Use of mobile health technologies to correlate activity, physiologic measures and environmental exposures with health outcomes; determination of the health impact of heterozygous loss of function mutations;
- Development new disease classifications and relationships;
- Empowerment of participants with data and information to improve their own health; and
- Creation of a platform to enable trials of targeted therapy.

Precision Medicine at Columbia University

Precision medicine in practice and research at Columbia University is realized via collaborations across all of our academic centers, ranging from law, business, ethics and engineering to the basic

sciences, converging on clinical practice. Our diverse scientific expertise readily contributes to enhancing precision medicine: genomics, proteomics, bioinformatics, systems biology, data and computational science, as well as core science, engineering, and other disciplines. The results should improve patient outcomes, reduce adverse treatment effects, and yield greater patient satisfaction.

In particular, Columbia University Medical Center's (CUMC's) efforts play a vital role in Columbia University's institution-wide priority to realize the potential of precision medicine. Through the efforts of the Precision Medicine Task Force, the University's internal expertise is coordinated and growing. The synergies of CUMC specialists' biomedical expertise with that of other University faculty and leaders will define the medical, legal, policy, and economic implications anticipated from the applications of precision medicine.

Many of the more than 40 state-of-the-art shared research facilities within CUMC participate in precision medicine initiatives. Already our discoveries are making a difference. For example, using genomic analysis, scientists sequence the DNA of individual tumors to find FDA-approved drugs likely to target crucial areas of each tumor's genetics. In addition, scientists developed a way to recreate an individual's immune system in a mouse, an unprecedented tool for customized analysis of autoimmune diseases such as type 1 diabetes. The tool also may be useful to analyze a patient's response to existing treatments or to develop new therapies.

Among CUMC's plans for precision medicine is a comprehensive biological repository that will store and allow analysis of 100,000 patient specimens to enable translational researchers to develop new therapies that, in turn, will transform the way clinicians diagnose and treat patients. Along with our clinical partner, the New York-Presbyterian Hospital, we are founding members of the New York Genome Center, which has brought together all of the New York academic, medical, and industry leaders in a consortium dedicated to translating genomic research into clinical solutions for treating disease.

Concluding Thoughts

The rising costs of drug development and healthcare in the U.S. suggest that a new model of clinical care is needed that will rely on robust and innovative health research. Drug discovery has slowed, and only a small fraction of proposed medications is successfully translated into approved and prescribed therapeutics. Clinical trials of new therapeutics may often be underpowered due to unrecognized heterogeneity in disease pathogenesis among enrolled patients such that drugs that are highly beneficial for a definable subset are rejected because the majority of patients in the trial fail to respond. The discovery of genetic factors underlying disease can be used to identify drug targets as well as to selectively give those drugs to patients that are most likely to have the greatest efficacy with the least adverse effects. Understanding the genetics of disease and biomarkers will allow us to rationally select patient groups that are most likely to respond to particular agents, not only improving "numbers" (e.g., lower cholesterol) but also improving health outcomes (e.g., reduced heart attacks) and quality of life.

To be successful, it would be ideal and cost effective to study a single, very large cohort that would provide sufficient power to study ostensibly all relatively common diseases within a single cohort. The barriers to such a study have been the relatively high cost of ascertaining cohort members, collecting comprehensive clinical and experimental data, and following participants over time. Over the last decade, however, a number of technological advances have converged to dramatically reduce

the barriers to the assembly, evaluation, and analysis of cohorts of one million or more people – including information technology improvements related to data storage and computation; vast improvements in DNA sequencing; and the emergence of electronic health records.

Given these rapid and ongoing transformations in medicine, technology, and society, the time is right for the U.S. to undertake an ambitious expanded research agenda focused on development and implementation of precision medicine to improve the health of the nation.

We urge the Subcommittee to provide the NIH with an appropriation totaling $34.5 billion to enable the NIH and its partners in the biomedical research enterprise to develop better, more targeted, more effective, and more efficient healthcare for society.

Thank you for the opportunity to provide this information to the Subcommittee.

Statement of Gregory E. Conrad, Executive Director, Interstate Mining Compact Commission Regarding the FY 2017 Budget Request of the Mine Safety and Health Administration (MSHA) Within the U.S. Department of Labor

Gregory E. Conrad, Executive Director
Interstate Mining Compact Commission
445 Carlisle Drive, Suite A, Herndon, VA 20170
Phone: (703) 709-8654
E-mail: gconrad@imcc.isa.us

Before the Subcommittee on Labor, Health and Human Services, Education and Related Agencies of the House Appropriations Committee

We are writing in support of the Fiscal Year 2017 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 request for state assistance grants is $8,441,000.1 While the proposed amount goes a long way in helping the states provide important safety training and is appreciated by the states, it is the same amount that has been appropriated for state assistance grants by Congress over the past several fiseal years and, as such, does not fully consider inflationary and programmatic increases being experienced by the states. We urge the subcommittee to restore funding to the statutorily authorized level of $10 million for state assistance grants so that states are able to meet the training needs of miners and to fully and effectively carry out state responsibilities under section 503(a) of the Act. We believe the states can justify thc 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 25 member states. The states are represented by their Governors who serve as Commissioners.

It should be kept in mind that, whereas MSHA over the years has narrowly interpreted state assistance grants as meaning "training grants" only, Section 503 was structured to be much broader in scope and to stand as a separate and distinct part of the overall mine safety and health program. In the Conference Report that accompanied passage of the Federal Coal Mining Health

---

1 MSHA's budget justification document does not directly reference an amount of $8.4 million for state assistance grants. In fact, there is some concern that the amount may in fact be $5 million given MSHA's reference in its budget document to an amount of $3.4 million for the purpose of "strengthen[ing] the delivery of training to MSHA and the mining industry to include expansion of the distance learning program and the development of audiovisual materials." MSHA assured the states at a meeting on March 2, 2016 that the $3.4 million is ***in addition to*** the $8.4 million for state training grants. We urge thc Subcommittee to confirm this in thc final appropriations bill.

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 in Congress.

With respect to the training component of our mine safety programs, IMCC's member states are concerned that without full, stable funding of the State Grants Program, the federally required training for miners employed throughout the U.S. will suffer. States are struggling to maintain efficient and effective miner training and certification programs in spite of increased numbers of trainees and the incremental costs associated therewith. The situation has been further complicated by new statutory, regulatory and policy requirements that have grown out of the various reports and recommendations attending the Upper Big Branch investigation. We greatly appreciate Congress' recognition of this fact and this Subcommittee's strong support for state assistance grants, especially in past years when the Administration sought to eliminate or substantially reduce those moneys.

Our experience over the past 35 years has demonstrated that the states are often in the best position to design and offer mine safety and health training in a way that insures that the goals and objectives of Sections 502 and 503 of the Mine Safety and Health Act are adequately met. MSHA estimates in its budget justification document (under Educational Policy and Development (EPD)) that the states will train approximately 180,000 miners in FY 2017. The most recent accounting of the number of miners trained via a sampling of the states based on FY 2014 reporting for coal and metal/nonmetal is as follows:

- **Kentucky:** Trained or tested over 17,758.
- **Alaska:** 1,119 miners trained.
- **New Mexico:** 1,942 miners trained.
- **Illinois:** 13,227 miners and contractors trained (including Aggregate Part 46, Coal Mine Accident Prevention, certification and EMT training).
- **Indiana:** 3,247 miners and contractors trained.
- **Oklahoma:** 4,180 miners trained.
- **Pennsylvania:** 6,535 miners trained.
- **Ohio:** 7,000 miners trained.
- **Colorado:** 4,731 miners trained.
- **Arkansas:** 2,573 miners and contractors trained.
- **Nevada:** 2,329 miners trained.
- **North Carolina:** 8,515 miners trained.
- **Maryland:** 452 miners trained (FY 2013).
- **Arizona:** 2,612 miners trained.
- **Virginia:** 4,940 miners trained and 2,422 certifications issued.
- **Mississippi:** 175 miners and contractors trained.

As you consider our request to increase MSHA=s budget for state training grants, please keep in mind that the states play a particularly critical role in providing special assistance to small mine operators (those coal mine operators who employ 50 or fewer miners or 20 or fewer miners in the metal/nonmetal area) and the Spanish-speaking community in meeting their required training needs.

We also want to bring another matter to your attention because of the implications it may have for mine safety and health programs, as well as related programs under the Surface Mining Control and Reclamation Act of 1977 (SMCRA). Recently, MSHA attempted to assert jurisdiction over an abandoned mine land (AML) project site being reclaimed by the Commonwealth of Pennsylvania as part of its approved AML program under Title IV of SMCRA. Because the project involves the incidental extraction of coal that will be removed from the site and sold (with the proceeds being reinvested in the project), MSHA believes this triggers its jurisdiction under the Mine Act.2 This is based on MSHA's argument that courts have held that "reclamation" of extraction sites is covered under the Mine Act Section 3(h) definition of "mine" because it restores lands, etc. whose condition is caused by ("resulting from") the work of extraction.

In an attempt to seek resolution regarding the appropriateness of MSHA jurisdiction over this class of AML projects, the states, through IMCC, have met on several occasions with both MSHA and OSM officials to discuss the matter. Since the inception of SMCRA in 1977 and the states' implementation of AML programs beginning in 1979, we are aware of rare circumstances where MSHA has asserted jurisdiction over these types of projects involving coal or noncoal reclamation except in those few circumstances where an AML contractor inadvertently requested an MSHA ID number. Even in those very limited situations, MSHA has seldom pursued inspection and enforcement once it realized an AML project was underway. We are therefore hopeful that MSHA will continue to constrain its involvement in AML projects, which are already regulated by the states, with federal oversight by OSM, and which are generally subject to OSHA jurisdiction. The consequences of a decision rendering these sites subject to MSHA jurisdiction could have debilitating consequences for the AML program under SMCRA and significant budgetary implications for MSHA. We therefore urge the Subcommittee to include language in its report on MSHA's budget prohibiting the agency from exercising jurisdiction over AML projects under Title IV of SMCRA.

---

2 The project is being undertaken pursuant to a duly promulgated rule by the Office of Surface Mining (OSM) under SMCRA authorizing these types of "AML enhancement projects". Since these types of projects began in 1999, MSHA has been very inconsistent in exercising jurisdiction over them.

March 11, 2016

The Honorable Harold Rogers
Chairman
Committee on Appropriations
U.S. House of Representatives
Washington, D.C., 20515

The Honorable Nita Lowey
Ranking Member
Committee on Appropriations
U.S. House of Representatives
Washington, D.C., 20515

The Honorable Tom Cole
Chairman
Subcommittee on Labor, HHS, & Education
U.S. House of Representatives
Washington, D.C., 20515

The Honorable Rosa DeLauro
Ranking Member
Subcommittee on Labor, HHS, & Education
U.S. House of Representatives
Washington, D.C., 20515

Dear Chairmen Rogers and Cole and Ranking Members Lowey and Delauro:

Biocom represents the Southern California life science ecosystem, which includes biopharmaceutical, medical device, and diagnostic companies, universities and research institutions, as well as service providers and patient groups. With more than 750 members dedicated to developing life-enhancing and life-saving treatments and cures for patients in need, Biocom leads advocacy efforts to positively influence the region's life science community in the development and delivery of innovative products.

In our mission of providing feedback and communication between legislators and industry, we write in support of additional funding for the National Institutes of Health (NIH). **Specifically, we urge the Committee to appropriate $34.5 billion for the agency in Fiscal Year 2017.**

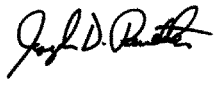
Basic research is the foundation for innovation and is crucial to the development of breakthrough therapies and technologies. Over the past 40 years, NIH-funded research has contributed to the discovery of over 150 new FDA-approved drugs, vaccines, or new indications for current drugs, and has been the driving force behind advances that were once unimaginable, such as sequencing the human genome. The federal investment of $3.8 billion in the Human Genome Project from 1988 to 2003 helped drive $796 billion in economic output. Overall, the NIH generates over $60 billion in economic activity every year, with every dollar in NIH funding generating over $2 dollars in local economic growth.

However, NIH funding has been flat for the past decade and has not kept pace with inflation, which has resulted in the NIH losing nearly 25 percent of its purchasing power. Decreased investments in innovation discourage talented individuals from pursuing careers in science, drive away early-stage investors, and lead some scientists to other countries to pursue research interests. As a result, research ideas and projects that could lead to potential cures will never be developed. The U.S. also risks losing its global leadership in science and medical innovation to countries such as China, India, and Russia, which are all increasing their R&D investments by double digits.

Last year, Congress allocated $32.1 billion to the NIH, an increase highly welcomed by Biocom. Congress must continue to invest in medical innovation and increase NIH funding to at least $34.5 billion in FY2017 to enable the development of breakthrough treatments and cures. We just cannot allow flat funding to undermine progress in medical research at a time when we are on the cusp of exciting new advances in cancer, infectious diseases including HIV/AIDS, heart disease, diabetes, Alzheimer's and many other diseases.

We appreciate the opportunity to provide feedback on behalf of our members and thank you for your time and diligence in examining our request. We look forward to continuing working with you on this very important matter.

Sincerely,



Joe Panetta
President and CEO
Biocom

Tyrone C. Spady, PhD
Director of Legislative and Public Affairs
American Society of Plant Biologists
tspady@aspb.org

American Society of Plant Biologists

Cultivating a better future through plant biology research

Official Written Testimony in Support of the National Institutes of Health's

Fiscal Year 2017 Budget

Subcommittee on Labor, Health and Human Services, Education, and Related Agencies

Committee on Appropriations

U.S. House of Representatives

April 15, 2016

On behalf of the American Society of Plant Biologists (ASPB), we would like to thank the Subcommittee for its support of the National Institutes of Health (NIH). ASPB and its members strongly believe that sustained investments in scientific research are a critical component of economic growth and job creation in our nation. ***ASPB supports the maximum fiscal year 2017 appropriation for NIH and asks that the Subcommittee Members encourage increased support for plant-related research within the agency;*** 25% of our medicines originate from discoveries related to plant natural products, and such research has contributed in innumerable ways to improving the lives and health of Americans and people throughout the world.

ASPB is an organization of professional plant biology researchers, educators, students, and postdoctoral scientists with members across the nation and throughout the world. A strong voice for the global plant science community, our mission—achieved through work in the realms of

research, education, and public policy—is to promote the growth and development of plant biology, to encourage and communicate research in plant biology, and to promote the interests and growth of plant scientists in general.

Plant Biology Research and America's Future

Among many other functions, plants form much of the base of the food chain upon which all life depends. Importantly, plant research is also helping make many fundamental contributions in the area of human health, including that of a sustainable supply and discovery of plant-derived pharmaceuticals, nutriceuticals, and alternative medicines. Plant research also contributes to the continued, sustainable, development of better and more nutritious foods and the understanding of basic biological principles that underpin improvements in the health and nutrition of all Americans.

Plant Biology and the National Institutes of Health

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

Many fundamental biological components and mechanisms (e.g., cell division, viral and bacterial invasion, polar growth, DNA methylation and repair, innate immunity signaling and circadian rhythms) are shared by both plants and animals. For example, a process known as RNA interference, which has potential application in the treatment of human disease, was first discovered in plants. Subsequent research eventually led to two American scientists, Andrew Fire and Craig Mello, earning the 2006 Nobel Prize in Physiology or Medicine. More recently, scientists engineered a class of proteins called TALENs capable of precisely editing genomes to potentially correct mutations that lead to disease. That these therapeutic proteins are derived from others initially discovered in a plant pathogen exemplifies the application of plant biology research to improving human health. These important discoveries again reflect the fact that some of the most important biological discoveries applicable to human physiology and medicine can find their origins in plant-related research endeavors.

Health and Nutrition – Plant biology research is also central to the application of basic knowledge to "extend healthy life and reduce the burdens of illness and disability." Without good nutrition, there cannot be good health. Indeed, a World Health Organization study on childhood nutrition in developing countries concluded that over 50% of child deaths under the age of five could be attributed to malnutrition's effects in weakening the immune system and exacerbating common illnesses such as respiratory infections and diarrhea. Strikingly, most of these deaths were not linked to severe malnutrition, but chronic nutritional deficiencies brought about by overreliance on single crops for primary staples. Plant researchers are working today to address the root cause of this problem by balancing the nutritional content of major crop plants to provide the full range of essential micronutrients in plant-based diets.

By contrast, obesity, cardiac disease, and cancer take a striking toll in the developed world. Research to improve and optimize concentrations of plant compounds known to have, for example, anti-carcinogenic properties, will hopefully help in reducing disease incidence rates. Ongoing development of crop varieties with tailored nutraceutical content is an important contribution that plant biologists can and are making toward realizing the long-awaited goal of personalized medicine, especially for preventative medicine.

Drug Discovery – Plants are also fundamentally important as sources of both extant drugs and drug discovery leads. In fact, 60% of anti-cancer drugs in use within the last decade are of natural product origin—plants being a significant source. An excellent example of the importance of plant-based pharmaceuticals is the anti-cancer drug taxol, which was discovered as an anti-carcinogenic compound from the bark of the Pacific yew tree through collaborative work involving scientists at the NIH National Cancer Institute and plant natural product chemists. Taxol is just one example of the many plant compounds that will continue to provide a fruitful source of new drug leads.

While the pharmaceutical industry has largely neglected natural products-based drug discovery in recent years, research support from NIH offers yet another paradigm. Multidisciplinary teams of plant biologists, bioinformaticians, and synthetic biologists are being assembled to develop new tools and methods for natural products discovery and creation of new pharmaceuticals. We appreciate NIH's current investment into understanding the biosynthesis of natural products through transcriptomics and metabolomics of medicinal plants and support more funding opportunities similar to the "Genomes to Natural Products" which will hopefully pave the way for new plant-related medicinal research.

Conclusion

Although NIH does recognize that plants serve many important roles, the boundaries of plant-related research are expansive and integrate seamlessly and synergistically with many different disciplines that are also highly relevant to NIH. As such, ***ASPB asks the Subcommittee to provide the maximum appropriation and direct NIH to support additional plant research in order to continue to pioneer new discoveries and new methods with applicability and relevance in biomedical research.***

Thank you for your consideration of ASPB's testimony. For more information about ASPB, please see www.aspb.org.

RAILROAD RETIREMENT BOARD
FISCAL YEAR 2017 BUDGET REQUEST
Statement for the Record, March 8, 2016

HOUSE COMMITTEE ON APPROPRIATIONS SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES, EDUCATION, AND RELATED AGENCIES

Vacant, Chairman of the Board
Walter A. Barrows, Labor Member of the Board
Steven J. Anthony, Management Member of the Board

Mr. Chairman and Members of the Committee:

We are pleased to present the following information to support the Railroad Retirement Board's (RRB) fiscal year 2017 budget request of $122,499,000 for our retirement, unemployment and other programs.

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

During fiscal year 2015, the RRB paid $12.2 billion, net of recoveries, in retirement/ survivor benefits to about 558,000 beneficiaries. We also paid $85.1 million in net unemployment/sickness insurance benefits to about 25,000 claimants. Temporary extended unemployment benefits paid were $8.625 million. In addition, the RRB paid benefits on behalf of the Social Security Administration amounting to $1.5 billion to about 111,000 beneficiaries.

PROPOSED FUNDING FOR AGENCY ADMINISTRATION

The RRB faces major challenges in its mission to pay benefits and serve as responsible stewards for our Customer's Trust funds and agency resources. Those areas of challenge include agency staffing, information technology, and program integrity. The President's proposed budget would provide $122,499,000 for agency operations. This level of funding includes $6.1 million toward a multi-year plan to re-engineer legacy mainframe applications while maintaining 850 full-time equivalents (FTEs). Historically, however, the enacted level of funding awarded to the RRB, has not been sufficient to implement significant improvements and initiatives in our most challenging areas. The remainder of this testimony will focus on these areas with a few additional topics in conclusion.

AGENCY STAFFING

The RRB's dedicated and experienced workforce is the foundation for our tradition of excellence in customer service and satisfaction. Eighty-percent of our administrative expense is

for labor. Like many Federal agencies, however, the RRB has a number of employees at or near retirement age. About 55 percent of our employees have 20 or more years of service, and over 40 percent of our current workforce will be eligible for retirement by Fiscal Year 2017. Based on trend analysis of our position index, hiring plans, and full-time equivalent (FTE) reporting of attritions and accessions from 2010 through 2016, the RRB has attrited half of its agency. Almost half of our staff has been replaced. The agency has been able to utilize the re-employment of retirees under the Civil Service and FERS to temporarily rehire under Section 1122(a) of Public Law 111-84 and assist in areas that have knowledge gaps due to attrition. The implementation of Learning Management System (LMS), an internet-based software package that provides comprehensive functionality for training administration, documentation, tracking, reporting and delivery of e-learning education and training programs supports the agency's efforts for continued excellence in our workforce. Although 850 is the FTE level the RRB can maintain for Fiscal Year 2017 President's Budget in order to leverage funds to support information technology (IT) and program integrity initiatives, the agency would be at-risk if such strategy was used for Fiscal Year 2018 and out-years as our attrition rate is expected to take a significant downturn from 7 separations/retirements per month to 4 separations/retirements per month now that half of our workforce over 6 years is replaced. At a minimum, the agency needs to be able to restore FTE funding to 860 starting with fiscal year 2018, and maintain an 885 FTE level in the out-years to address our most vital costs, which is sustaining our workforce.

INFORMATION TECHNOLOGY IMPROVEMENTS

The President and the Office of Management and Budget (OMB) have challenged agencies to create a 21st Century Government. Although we are not a CFO Act agency, we are classified as a significant entity for federal government audit and reporting purposes. The RRB has chosen to be progressive in implementing initiatives and improvements. In Fiscal Year 2017, $6.1 million in IT requested funding is targeted toward system modernization to re-engineer mainframe applications that build on prior year investments. Fiscal year 2016 enacted funding provided no such investments. As a result, the agency is taking risk in the current year of $2 million in support of the agency's critical need to migrate over 14 million lines of common business-oriented language (COBOL) code that support more than 4,200 custom programs included in 200 major application systems. We awarded a contract in Fiscal Year 2015 to implement the conversion, subject to funds availability. We have taken risk in our Fiscal Year 2016 Operating Plan to leverage funds of $2 million towards this legacy benefit system modernization contract. We took this risk because in addition to mitigating cybersecurity risks of operating legacy systems, enhancing data analytics capabilities towards stronger program integrity measures, and creating 26 FTE savings that can be accrued from change in business processes, a large number of the agency's technology employees are at or nearing retirement age. As the years go by, the skills required to enhance and maintain legacy benefit systems, especially developers with COBOL skills, will be hard to find. By re-engineering the applications, we mitigate the inherent risks of an aging workforce of which 40 percent can retire today, some taking with them the institutional knowledge of over 40 years. Given that technology advances rapidly, it is essential that we have the ability to modernize business applications.

Fiscal year 2017 funding of $6.1 million for legacy benefit system modernization, if received, will re-engineer critical legacy mainframe applications to sustain agency operations

and enable a future ready RRB workforce equipped with modern tools and technologies to do their jobs in the most efficient and effective manner that leads to sustained customer satisfaction in the railroad community. The RRB would be able to revolutionize the current applications development environment to make it flexible to accommodate change and embrace new technologies. Each year that enacted funding does not equal the agency's request for system modernization, contract work will have to stop as we enter Fiscal Year 2017 and jeopardizes the success of the on-going project.

PROGRAM INTEGRITY

Fiscal year 2017 President's Budget also provides approximately $4.3 million in mandatory no-year funding for the RRB's program integrity activities. In light of recent fraud events that have impacted the agency, the RRB must increase staff disability oversight, improve existing program integrity functions, and implement initiatives to target groups of annuitants most likely to commit medical and/or earnings fraud. The proposed $4.3 million was determined based on a review of current operations as well as disability recommendations from the Government Accountability Office and the RRB's Office of the Inspector General. The RRB takes its program integrity initiatives very serious and increased its standards significantly. These new standards come at a cost greater than what the agency continually absorbs from enacted funds provided. In the current fiscal year, the agency has experienced increased costs of at least $2.5 million in the area of medical examinations, training and staffing. As long as we continue to absorb program integrity cost increases in our baseline budget without receiving mandatory funding, the RRB risks having to halt system modernization efforts and perform fragmented staffing efforts of workforce after fiscal year 2017.

The proposed funding is for staffing costs and contractual costs. Augmented staff includes four people dedicated to quality assurance and seven people dedicated to program evaluation through such activities as oversight of fraud prevention initiatives, special studies, and the development and implementation of enhanced procedures critical to program integrity. An additional six employees will support enhanced emphasis on initial eligibility and continuing entitlement to benefits. A Chief Medical Officer will be hired to provide assistance and guidance to agency staff in the adjudication of disability claims, work with our medical contractors and develop processes to ensure disability examiners have updated training. Contractor costs include on-going annual fraud training for employees at all levels of the organization and confirming medical exams for all initial disability applications.

The RRB has proven to be a good investment for program integrity over the years. Our program integrity efforts save the Trust Fund from which railroad benefits are paid an estimated $4.49 for each $1 spent on program integrity activities.

LEGISLATIVE PROPOSALS

In connection with these workforce planning efforts, the President's budget request includes a legislative proposal to enable the RRB to utilize various hiring authorities available to other Federal agencies. Section 7(b) (9) of the Railroad Retirement Act contains language requiring that all employees of the RRB, except for one assistant for each Board Member, must be hired under the competitive civil service. We propose to eliminate this requirement, thereby

enabling the RRB to use various hiring authorities offered by the Office of Personnel Management.

Our budget request includes two additional legislative proposals. The first is to amend the RRA and the RUIA to include a felony charge for individuals committing fraud against the agency. The second is to amend the Social Security Act to provide access for the RRB to the National Directory of New Hires (NDNH). Access to NDNH supports the RRB's integrity efforts to prevent improper payments.

FINANCIAL STATUS OF THE TRUST FUNDS

Railroad Retirement Accounts – The RRB continues to coordinate its activities with the National Railroad Retirement Investment Trust (Trust), which was established by the Railroad Retirement and Survivors' Improvement Act of 2001 (RRSIA) to manage and invest railroad retirement assets. Pursuant to the RRSIA, the RRB has transferred a total of $21.276 billion to the Trust. All of these transfers were made in fiscal years 2002 through 2004. The Trust has invested the transferred funds, and the results of these investments are reported to the RRB and posted periodically on the RRB's website. The net asset value of Trust-managed assets on September 30, 2015, was approximately $24.5 billion, a decrease of almost $1.6 billion from the previous year. Through February 2016, the Trust had transferred approximately $18.3 billion to the Railroad Retirement Board for payment of railroad retirement benefits.

The RRB's latest report required by the Railroad Retirement Act of 1974 and Railroad Retirement Solvency Act of 1983 was released in September 2015. The overall conclusion is, barring a sudden, unanticipated, large decrease in railroad employment or substantial investment losses, the railroad retirement system will experience no cash flow problems during the next 32 years. The report recommended no change in the rate of tax imposed on employers and employees. The tax adjustment mechanism will automatically increase or decrease tax rates in response to changes in fund balance. Only under the most pessimistic employment assumption does the tax rate mechanism not avoid cash flow problems.

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 2015. The report indicated that even as maximum daily benefit rates rose approximately 39 percent (from $70 to $97) from 2014 to 2025, 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.

Testimony submitted on behalf of the American Physiological Society
Patricia E. Molina, Ph.D., President

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 FY 2016 provided a much needed restoration of resources at a critical time, but great challenges are still before us. In order to continue meeting those challenges, the APS urges you to make every effort to provide the NIH with at least $35 billion in FY 2017.

Federal investment in research is critically important because breakthroughs in basic and translational research are the foundation for new drugs and therapies that help patients, fuel our economy, and provide jobs. Moreover, the federal government is the primary funding source for discovery research through competitive grants awarded by the NIH. The private sector may develop new treatments, but it relies upon federally-funded research to identify where innovation opportunities can be found. This system of public-private partnership has been critical to U.S. leadership in the biomedical sciences. However, this position of leadership is at risk because other nations have been increasing their investments in research and development while the United States investment has been stagnant.

Federal research dollars also have a significant impact at the local level: Approximately 84% of the NIH budget is awarded throughout the country to some 35,000 researchers. They in turn use these grant funds to pay research and administrative staff, purchase supplies and equipment, and cover other costs associated with their research.

The $2 billion increase provided for FY 2016 was an important first step toward correcting the effects of sequestration and several years of declining budgets at the NIH. To set the agency on a more sustainable path forward, we urge you to provide predictable annual budget increases that will allow the scientific enterprise to keep up with the rate of inflation and move in new directions.

The FY 2017 budget request for the NIH highlights important initiatives for the agency, including the National Cancer Moonshot, the Precision Medicine Initiative and the Brain Research through Advancing Innovative Neurotechnologies (BRAIN) Initiative. These initiatives will focus resources on critical areas of scientific opportunity that are ripe for innovation, but it is important to bear in mind that these projects are only possible because of decades of basic research. NIH must continue to invest in creative investigator-initiated research to advance our knowledge and create future opportunities for innovation.

Over the past several decades, NIH has used a merit-based peer review system to identify and fund the best research proposals. As a result, Americans can expect to live longer and healthier lives. However, significant challenges still loom for our nation: Researchers are already working to understand emerging diseases such as the Zika virus; learning how it spreads, what effects it has on people who become infected, and what sort of threat it poses in the United States. An aging population will continue to strain an already stressed system of health care in the US. As the baby boom generation continues to age, we can expect to see increases in diseases that affect an aging population including diabetes, heart disease, and cancer. Developing better ways to

detect and treat these diseases will reduce disease burden and ultimately help manage the strain that will be placed on the American health care system. To continue to be able to address these and other challenges, the NIH needs additional resources.

This year the NIH issued the agency's first ever NIH-wide Strategic Plan[1]. This document lays out NIH's plans to address the needs of the nation while maximizing scientific opportunity and supporting the biomedical research enterprise. Implementing the plan will require predictable, sustainable funding increases over the next several years. The APS joins the Federation of American Societies for Experimental Biology (FASEB) in urging that NIH be provided with no less than $35 billion in FY 2017.

The American Physiological Society is a professional society dedicated to fostering research and education as well as the dissemination of scientific knowledge concerning how the organs and systems of the body work. The Society was founded in 1887 and now has more than 10,000 member physiologists. APS members conduct NIH-supported research at colleges, universities, medical schools, and other public and private research institutions across the U.S.

[1]http://www.nih.gov/sites/default/files/about-nih/strategic-plan-fy2016-2020-508.pdf

My name is Patti Gustafson, mother of Michael Gustafson, who started the Swifty Foundation before his death from medullablastoma, a pediatric brain tumor. Michael started Swifty because he didn't want any other child to have to go through what he did in his years of living with cancer. Michael was diagnosed at age 10 and died at 15. He was treated with drugs that were 30-40 years old, because there have been so few drugs developed for pediatric cancers in that time. Swifty's mission is to raise awareness and funds for pediatric cancer research. Michael was appalled to discover only 4 pennies of every dollar available for federally funded cancer research is used to fund pediatric cancer research. He wondered at the lack of caring and compassion for the most vulnerable of cancer patients, children like himself.

NIH receives $30+ billion in appropriations. Of that amount the national cancer institute gets $5 billion of which childhood cancer research gets around $200 million. Childhood cancer is the #1 disease related killer of kids in the US and the incidence of childhood cancer has been steadily rising. Today 1 in 285 children will be diagnosed with cancer before they reach the age of 20. Adult cancers and childhood cancers are different. We need investment in childhood cancer now to give kids the cures they deserve. Childhood cancer research should be a priority In The NIH budget not an afterthought.

Michael's twin sister, Bridget will be graduating in two months.... alone, without her brother. How many other kids have to die before this country does the right thing for kids who can't fight for themselves against big pharma, politicians and ignorance? It's up to our government, our state representatives to be the voice for the voiceless. That's why we voted you in to represent us! Here from the childhood cancer community.... the time is now to fund Childhood cancer have give these kids a chance!

Sincerely,
Patti Gustafson
Swifty Foundation

VOR
Speaking out for people with intellectual & developmental disabilities

VOR
836 S. Arlington Heights Rd.
No. 351
Elk Grove Village, IL 60007
Toll Free: 877.399.4867
www.vor.net

President
Ann Knighton
PO Box 10005
Augusta, GA 30903
706.993.6329

Executive Director
Hugo Dwyer
72 Carmine St.
New York, NY 10014
646.387.2267
hdwyer@vor.net

March 28, 2016

Organization Submitting Testimony:
VOR, *Speaking out for people with intellectual and developmental disabilities*
Contact: Hugo Dwyer, Executive Director; (646) 387-2267; hdwyer@vor.net

Testimony Prepared For:
Subcommittee on Labor, Health and Human Services, and Education, and Related Agencies, U.S. House Committee on Appropriations (lh.approp@mail.house.gov)

Subject: FY 2017 written testimony for the record
U.S. Department of Health and Human Services (HHS) Agencies, including the Administration on Intellectual and Developmental Disabilities (AIDD)

I. Introduction

VOR is a national nonprofit organization advocating for high quality care in a full continuum of residential options and human rights for all people with intellectual and developmental disabilities (I/DD).

It has been 16 years since the Developmental Disabilities Assistance and Bill of Rights Act (DD Act) has been reauthorized. During that time, the AIDD and its state-based DD Act programs have engaged in activities designed to elose intermediate care facilities for individuals with I/DD (ICFs/IID) against the wishes of the legal guardians of the residents, disregarding the plain language of the Americans with Disabilities Act (ADA) and the *Olmstead* decision. Too often the results have been disastrous for the residents, resulting in ahuse, neglect and even death. For the past nine years, absent reauthorization of the DD Act, these programs have been able to continue to ignore the will of the Congress and the governing Supreme Court ruling only through the appropriations process.

Therefore, VOR requests that the Subcommittee include language in the FY 2017 Labor, HHS, and Education and Related Agencies Appropriations bill to begin the process of stopping these abuses. Specifically, VOR requests inclusion of language that expressly **prohibits the use of appropriations for any HHS program to bring a lawsuit to close an ICF/IID, unless the program has first notified the affected individuals and their legal guardians and HHS has submitted reports to the Committee showing how it respects the wishes of the families and provides comparable care of the individuals with I/DD in the community in close proximity to their families and their support community.** Suggested language to accomplish these purposes is included at the end of the testimony.

As explained below, we strongly believe such forced deinstitutionalization class action lawsuits are contrary to federal law and cause human harm. These suits

should really be labeled HHS v. HHS, as one HHS-funded program (Protection and Advocacy) is essentially suing another HHS program (CMS, which certifies, funds and monitors ICFs/IID). These HHS deinstitutionalization activities are a cruel, absurd and wasteful use of federal funding.

Tragedies are widespread and predictable when fragile citizens are removed from specialized care. The legally-protected rights of families and legal guardians to serve as the primary decisionmakers for their loved ones with I/DD are routinely ignored. HHS says these class action suits are enforcing the ADA, yet the plain language of that statute and the clear wording of *Olmstead* say otherwise. With no Congressional oversight of these actions in 16 years, we think an appropriate first step to reining them in is to request reports about how they are carrying out their activities

II. The Law: The *Olmstead* Decision, Medicaid Law, and the DD Act Protect Choice Based on Individual Need

HHS-funded organizations pursuing forced deinstitutionalization cite the landmark Supreme Court decision of ***Olmstead v L.C.*** (1999) as justification for its position to close the HHS-funded ICF/IID homes of individuals with I/DD. Like many organizations that support deinstitutionalization, these federal agencies misread and misapply the *Olmstead* decision's requirements. The Supreme Court is clear in its holding that the ADA requires individual choice before community placement can be imposed and recognizes the need for specialized care:

> **"We emphasize that nothing in the ADA or its implementing regulations condones termination of institutional settings for persons unable to handle or benefit from community settings .... Nor is there any federal requirement that community-based treatment be imposed on patients who do not desire it."** *Olmstead*, 527 U.S. 581, 601-02 (majority) (emphasis added)
>
> **"As already observed [by the majority], the ADA is not reasonably read to impel States to phase out institutions, placing patients in need of close care at risk .... 'Each disabled person is entitled to treatment in the most integrated setting possible for that person — recognizing on a case-by-case basis, that setting may be an institution'**[quoting VOR's *Amici Curiae* brief]." *Id.* at 605 (plurality).[1] (emphasis added)

Likewise, **Medicaid law** and regulations require that ICF/IID residents be "[g]iven the choice of either institutional or home and community-based services." 42 C.F.R. §441.302(d)(2); see also, 42 U.S.C.§1396n(c)(2)(C) and 42 C.F.R. §441.303.

The **DD Act**, which authorizes for funding AIDD programs, such as P & A Agencies, and related Congressional history, support residential choice and recognize that individuals and their families are in the best position to make care decisions:

[1]The Olmstead Decision has been Misinterpreted, http://www.vor.net/images/OlmsteadRedefined_final.pdf

"Individuals with developmental disabilities and their families are the primary decisionmakers regarding the services and supports such individuals and their families receive, including regarding choosing where the individuals live from available options, and play decisionmaking roles in policies and programs that affect the lives of such individuals and their families." DD Act, 42 U.S.C. 15001(c)(3)(2000).

"[T]he goals expressed in this Act to promote the greatest possible integration and independence for some individuals with developmental disabilities may not be read as a Federal policy supporting the closure of residential institutions" [H. Rep. 103-442 (March 21, 1994)].

III. Using HHS Funds to Eliminate HHS-Supported Homes Causing Human Harm: The AIDD and its state- based DD Act Programs

As noted above, it has been 16 years since Congress last reauthorized the DD Act. Authorizations for DD Act appropriations expired in 2007; however, Congress continues to fund these programs through the appropriations process. DD Act programs, including P&A, operate in every state. AIDD, within HHS, administers the DD Act programs.

Independent oversight of the AIDD and its programs is nearly non-existent,[2] enabling them to continue to flout the law. AIDD persists in its support for DD Act programs' deinstitutionalization activities and even proposed a recommendation to "[d]evelop and implement plans to close public and private institutions," and "[k]eep people with disabilities out of congregate institutions," in collaboration with DOJ and The Arc (2011). The programs do not solicit nor respect the views of families who select ICFs/IID homes for their loved ones, referring to them as "clueless" and "unaware,"[3] a view not shared by the Supreme Court (*see, Heller v. Doe,* 509 U.S. 312, 329 (1993) ("close relatives and guardians, both of whom likely have intimate knowledge of a mentally retarded person's abilities and experiences, have valuable insights which should be considered during the involuntary commitment process."). With AIDD directive, state-level DD Act program deinstitutionalization activities continue, exacting great harm on the very people Congress entrusted these HHS-entities to protect.

In a recent example, in 2014, Disability Rights Ohio (DRO), the State's P&A, cited *Olmstead* and threatened a class action lawsuit purportedly on behalf of thousands of Ohioans with I/DD who receive care and support in licensed state and private ICFs/IID, sheltered workshops, or day program settings (July 1, 2014 letter to state officials). Ignoring the "primary decisionmakers" language of its authorizing statute, the DD Act, and without consulting with the individuals and families residing in the ICFs/IID, DRO instead cited the experiences of three individuals with disabilities to make the case that "thousands" are equally unsatisfied with their present situations. DRO's allegations and threats of litigation prompted draconian budget proposals that would have forced thousands of individuals with

[2] See, VOR Federal Comments Urging Objective Performance - Not More Self-Reporting - of DD Act Programs (January 25, 2012)(vor.net/images/VORCommentDDActEvaluationJan2012.pdf)

[3] June 14, 2010 and July 30, 2007 letters to Congress referring to families as "unaware" and "clueless," respectively.

profound disabilities from their homes, workplaces, and day program settings.

The primary decisionmakers strongly disagreed with DRO's allegations and threats. Over 21,000 families signed a petition objecting to the budget proposals and many testified, prompting legislators to ask "who does DRO speak for?" Once again ignoring the wishes of the people DRO is supposed to protect, on March 26, 2015, DRO reiterated its threat, writing, "Without the complete package of reforms laid out in the proposed budget, there would be no foundation for a future agreement and no alternative for class members but to pursue their claims in court." (March 26, 2015 letter to state officials). Even after the legislators and Governor Kasich rejected DRO's proposed "reforms," DRO now plans to file a lawsuit against Ohio's developmental disabilities service system. The suit could affect services for tens of thousands people with I/DD despite their demonstrated opposition, the opposition of the State of Ohio, and the clear language of the DD Act, the ADA and *Olmstead.* It is time to rein in these lawless, anti-democratic entities who view themselves as above the law.

Lawsuits have been a favorite tool of P&As over the years, so DRO's fear mongering comes as no surprise. Since 1996, P&A has filed more than 15 class action lawsuits seeking closure (*not* relating to conditions of care) over the objection of residents and their families. The P&A class action lawsuits are a particularly egregious use of federal funds; **they equate HHS suing itself** because the targets of these HHS-funded lawsuits are HHS/Medicaid-licensed ICFs/IID.

AIDD and its state-based programs persist in their ideological devotion to community placement despite **reports of an extraordinary death rate of nearly 16%** in Georgia (*Augusta Chronicle*, January 27, 2016); a doubling of the mortality rate for individuals moved from ICFs/IID to the community in Virginia (Dr. Robert Anthony, 2015); 1,200 "unnatural and unknown" deaths in New York (*New York Times*, 2011-2012); a risk of mortality in community settings of up to 88% in California (peer reviewed studies, 1996-2005); more than 100 deaths in Connecticut (Hartford Courant, March 2013); 53 deaths in Illinois (*Belleville News-Democrat*, June 27, 2012); hundreds of deaths in the District of Columbia (Washington Post, reports since 1999); plus many more reports of abuse, neglect and death across the majority of all states (*see e.g.* Widespread Abuse, Neglect and Death in Small Settings Serving People with Intellectual Disabilities (VOR, 2015)).

IV. Conclusion and Solution

Reauthorization of the DD Act is the appropriate place for a comprehensive review of HHS activities to determine if the programs they fund are operating within the spirit and letter of relevant law. In the meantime, as the DD Act programs will be funded through the appropriations process for the tenth year in a row, VOR believes it is proper and necessary to require the programs to take certain actions to inform the Congress of how they are operating. VOR's requests build on previous actions by this Committee. In FY 2016, the Omnibus Appropriations Act required that P&A provide affected individuals and their families with notice of any action that P&A would initiate on their behalf. We request that the Committee continue this requirement in FY 2017. The FY 2016 appropriations also

included language that "strongly urged [HHS] to continue to factor the needs and desire of patients, their families, caregivers, and other stakeholders, as well as the need to provide proper settings for care, into its enforcement of the Developmental Disabilities Act." Nearly identical language was also included in the FY 2016 Commerce, Justice appropriations. VOR doubts that HHS is, in fact, taking these actions and requests the Committee to require HHS to submit reports to Congress with respect to each of these areas so the Congress can start the process of determining whether and/or how HHS is meeting its obligations to respect the right of choice and make sure proper care is provided for those who leave ICFs/IID.

V. Requested Legislative Language

"Provided further, That none of the funds made available under this heading may be used by an eligible system (as defined in section 102 of the Protection and Advocacy for Individuals with Mental Illness Act (42 U.S.C. 10802)) to initiate or continue to pursue any legal action in a Federal or State court on behalf of an individual or group of individuals with a developmental disability (as defined in section 102(8)(A) of the Developmental Disabilities and Assistance and Bill of Rights Act of 2000 (20 U.S.C. 15002(8)(A)) that is attributable to a mental or physical impairment (or a combination of mental and physical impairments), that has as the requested remedy the closure of a Medicaid-licensed facility for people with intellectual or developmental disabilities, unless (1) reasonable public notice of the action has been provided to such individuals (or, in the case of mental incapacitation, the legal guardians who have been specifically awarded authority by the courts to make healthcare and residential decisions on behalf of such individuals) who are affected by such action, within 90 days of instituting such legal action, which informs such individuals (or such legal guardians) of their legal rights and how to exercise such rights consistent with current Federal Rules of Civil Procedure; and (2) the Department of Health and Human Services has submitted a report that indicates how it determines and respects the needs and desires of patients, their families and caregivers before taking any action, in accordance with the *Olmstead* decision, and what provisions it includes in any agreement with a State to assure that community residences that provide comparable care are in place before such individuals are moved, and that such residences are located near the resident's family and support community."

Statement of the Institute of Makers of Explosives
Submitted by: John Boling, Director of Government Affairs
For the Subcommittee on Labor, Health & Human Services, Education and Related Agencies
United States House of Representatives
March 28, 2016

FY 2017 Congressional Budget Justification for the Occupational Safety & Health Administration and the Mine Safety & Health Administration

Interest of the IME

The Institute of Makers of Explosives (IME) was founded in 1913 to provide accurate information and comprehensive recommendations concerning the safety and security of the commercial explosives industry. Our mission is to promote safety, and the protection of users, the public and environment, and to encourage the adoption of uniform rules and regulations in the manufacture, transportation, storage, handling, use and disposal of explosive materials used in blasting and other essential operations.

IME represents the U.S. manufacturers and distributors of commercial explosive materials and oxidizers as well as other companies that that provide related services. Millions of metric tons of high explosives, blasting agents, and oxidizers are consumed annually in the U.S. Of this, IME member companies produce over 98 percent of the high explosives and a great majority of the blasting agents and oxidizers. These products are used in every state and are distributed worldwide.

IME also publishes industry best practice standards in its Safety Library Publications (SLPs). These standards have been incorporated in Federal and state regulations and are used internationally. In addition, IME publishes a number of guidance documents on various subjects, such as our *Safety and Security Guidelines for Ammonium Nitrate*[1] and has produced several DVDs, including a DVD and Leader's Guide for first responders detailing the proper response to transportation incidents involving explosive materials.[2] The SLPs are regularly reviewed and updated by the Institute and represent the most current, reliable and expert recommendations on explosives management available to the industry.

In addition, IME has developed a comprehensive quantitative risk assessment (QRA) software program, IMESAFR. The program is a windows-based computer model for assessing the risk from a variety of commercial explosives activities as an alternative to determining safe setback distances based on decades old quantity-distance tables. IMESAFR is a state-of-the-art, tool that, will prove invaluable to the commercial explosives industry in our continuing mission to ensure the health, safety and security of present and future generations of explosive managers, the public and the environment.

---

[1] Safety and Security Guidelines for Ammonium Nitrate; IME, International Association of Fire Chiefs (IAFC), International Association of Explosive Engineers (ISEE), and the National Stone, Sand & Gravel Association (NSSGA), (2013).

[2] Responding to Highway Incidents Involving Commercial Explosives, IME and Department of Transportation (2013).

Comments
The following comments reflect our commitment to worker and public safety.

Occupational Safety & Health Administration (OSHA)

IME would like to express our thanks to the Committee for including in the FY 16 conference report the following language:

> **"The Committee understands that OSHA is reviewing its standards related to the storage of ammonium nitrate and urges OSHA to propose any necessary changes under existing regulations on Explosives and Blasting Agents (29 C.F.R. 1910.109) and not to add ammonium nitrate to the list of chemicals covered under OSHA's Process Safety Management Standards of Highly Hazardous Chemicals (29 C.F.R. 1910.119). The Committee believes that changes to improve the safety of storing ammonium nitrate should be made based on scientific review of current standards rather than through a one-size-fits-all approach under OSHA's Process Safety Management Standards."**

We regret to inform you that despite this clear direction, OSHA has determined to include the option of regulating AN within the scope of its recently proposed rulemaking, "Process Safety Management and Prevention of Major Chemical Accidents (RIN: 1218-AC83)." Consequently, we urge the Subcommittee to retain this language in the committee report for the FY 17 Labor, Health and Human Services, and Education appropriations bill.

This language was necessitated by section 6(c) of Executive Order 13650, which among other things, instructed OSHA to determine if Process Safety Management (PSM) can and should be expanded to cover AN. IME supports the continued reliance on the §1910.109(i) standard, and updating this standard to match current industry best practices. The updates include; (1) a prohibition on the use of wooden storage bins, (2) an instruction that fires involving AN should not be fought (our recommendation against fighting AN fires is aimed at offsite first responders, not to trained, in-house fire brigades that respond to emergencies in accordance with facility emergency action plans), and (3) a requirement that facilities prepare written emergency response plans and share these plans with the local emergency responder community. These recommendations are included in the previously mentioned IME *Safety & Security Guidelines for Ammonium Nitrate* (2013), and are largely consistent with the 2016 National Fire Protection Association (NFPA) 400 standard.

Current §1910.109(i) rules have proven very effective. Since the standard was promulgated in 1971, there has not been an accidental detonation of AN at any facility compliant with this regulation. A 45-year record of safety is, in our opinion, a good reason to strengthen the regulations, rather than impose the PSM standard on the industry.

Not only do the current regulations work, applying PSM in our opinion, is inappropriate and is not likely to increase safety in proportion with greatly increased compliance efforts that would be required. The PSM program was developed to prevent the release of highly dangerous chemicals like those released in the catastrophic accident in Bhopal, India, and AN is simply not a highly

dangerous chemical. The "technical" grade of AN used in the explosives industry has the same chemical composition as the "fertilizer" grade of AN used in the agricultural sector, only the density of the prill is different. AN, in either form, is not a volatile or self-reactive chemical requiring constant diligence in its handling. Rather, it is a stable, relatively benign substance when it is managed properly – and proper management of AN is simple, well understood, and easily accomplished. AN does not pose a threat of an accidental release of energy or fumes unless subjected to substantial and sustained heat (e.g., fire), contamination, or shock from high impact projectiles.

Considering that most IME members are small businesses, as defined by the Small Business Administration, the workload requirements associated with a PSM standard would fall hard on the industry. The PSM standard requires employers to complete 14 hazard assessment actions related to chemical processes, and completing these steps would likely require hiring additional employees or contractors. IME expects that these process hazard analyses ("PHAs") will conclude that compliance with the current standard at 29 C.F.R. 1910.109(i) will be sufficient to ensure that AN is safely stored and managed. Just to be clear, AN is also subject to a number of other ATF, EPA, DHS, and DOT safety and security regulations. Updating the current regulations will provide clear and actionable steps that can be taken to ensure safety of workers and the public, without the substantial and reoccurring financial burden that compliance with PSM would require.

Mine Safety & Health Administration
The FY 2017 budget request for MSHA contains two initiatives that we support.

- Safety Alliances

IME is in advanced stages of discussion to formally enter into a voluntary alliance with MSHA to promote safety across the commercial explosives sector. MSHA's Alliance Program enables organizations, like IME, that are committed to mine safety and health to collaborate with MSHA to prevent injuries and illnesses in the workplace. Through the program, MSHA and its allies work together to reach out to, educate, and lead the nation's mine operators and miners in improving and advancing mine safety and health. Alliances are formed by MSHA senior headquarters staff after initial discussions with an organization interested in collaborating with MSHA. While the safety statistics classified under *Explosives and Breaking Agents* by MSHA are exemplary, IME believes that safety should never take a rest. We look forward to reaching an agreement to work with MSHA to promote safety across the entire commercial explosives industry.

- Rules to Live By

IME recognizes that advancement in technology allows our membership to access training resources on their own schedule and across multiple platforms. In 2015, IME rolled out a new website that will adjust to the users' device allowing IME members and non-members to access our safety materials wherever and whenever they choose and on the device of their choice. For this reason, we applaud MSHA for innovative initiatives like "Rules to Live By" where the agency is using multiple platforms to promote safety. By putting knowledge and best practices literally at users' fingertips, both IME and MSHA can add a level of safety by directly empowering employees with the knowledge and understanding they need to stay safe. We are

hopeful that the Committee will support MSHA's continuing efforts to increase workers' knowledge base of safety through this initiative in FY 2017.

Thank you for your attention to these requests.

Testimony of the Physician Assistant Education Association (PAEA)
Concerning HRSA's Title VII Health Professions Programs

Submitted for the Record to the House Appropriations Subcommittee on
Labor, Health and Human Services, Education and Related Agencies – March 23, 2016

Submitted by: Anthony Miller, M.Ed., PA-C, Chief Policy and Research Officer
tmiller@paeaonline.org, 703-667-4339

On behalf of the 199 accredited physician assistant (PA) education programs in the United States, the Physician Assistant Education Association (PAEA) is pleased to submit this statement on the fiscal year (FY) 2017 appropriations. PAEA supports funding of at least $280 million in FY 2017 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). We also request that $12 million of that funding support PA programs operating across the country. This relatively small investment will reinforce the capacity of physician assistant education, and will greatly enhance PA educational programs. Title VII funding is the only designated source of federal funding for PA education. This funding is crucial to the U.S. PA education system's ability to meet the demand for PAs and produce highly skilled PAs ready to enter the health care workforce in an average of 27 months.

Need for Increased Federal Funding

The unmet need for primary care services in the United States is well documented. In fact, the need for primary care services is expected to grow as the population ages and requires more health care services especially as formerly uninsured patients gain access. Health care systems are rapidly evolving; amidst this change; the need for qualified health care providers in numbers sufficient enough to meet the demand remains a constant concern. Primary care has been clearly identified as the critical entry point into the health care system where access must be guaranteed. The PA profession was created specifically to address a shortage of primary care physicians almost fifty years ago. Today's PAs continue this tradition and stand ready to help address the challenges our nation faces in primary care and other specialties. The effectiveness of physician assistants is seen in better patient access, especially for Medicaid patients; high patient satisfaction; and health care outcomes similar to physicians. Importantly, PAs could play an even larger role in high-quality, cost-effective care with stronger federal support and through innovations in the PA education system.

Like physicians, the PA profession faces a shortage of graduates that will hinder its ability to help fully address the primary care issue in the United States. Without new solutions, at the current output of approximately 8,000 PA graduates annually, these shortages will persist, particularly in the rural and underserved communities where care is most needed.

Background on the Profession

Since the 1960s, PAs have consistently demonstrated they are effective partners in health care, readily adaptable to the needs of an ever-changing delivery system. Physician assistants are licensed health professionals with advanced education in general medicine that practice medicine as members of the healthcare team. They provide a broad range of medical and therapeutic services to diverse populations in rural and urban settings, including prescriptive authority in all 50 states, the District of Columbia, and Guam. PAs practice medicine to the extent allowed by law and within

Physician Assistant Education Association
655 K Street NW, Suite 700, Washington, DC 2001- 2385 Tel. (703) 548-5538
www.PAEAonline.org

the physician's scope of practice. Their combination of medical training, advanced education, and hands-on experience allows PAs to practice with significant autonomy, and in rural and other medically underserved areas where they are often the only full-time medical provider. The profession is well established, yet nimble enough to embrace new models of care, adopt innovative approaches to training and education, and adapt to health system challenges.

PA Education: The Pipeline for Physician Assistants

There are currently 199 accredited PA education programs in the United States. Together these programs graduate close to 8,000 PA students each year. PAs are educated as generalists in medicine, which gives them the flexibility to practice in more than 60 medical and surgical specialties. Approximately one third of PAs are working in primary care. The average PA education program is 27 months in length and includes one didactic year in the classroom, and another year devoted to clinical rotations. Most curricula include 340 hours of basic sciences and nearly 2,000 hours of clinical training, second only to physicians in time spent in clinical study.

As of today, approximately 55 new PA programs are in the pipeline at various stages of development and moving toward accredited status. The growth rate in the applicant pool is even more pronounced. Since its inception, the Centralized Application Service (CASPA) used by most programs grew from 4,669 applicants to over 20,000. As of March 2015, there were 22,997 applicants to PA education programs, which represents more than a 40% increase in CASPA applicants over the past five years alone.

The PA profession is expected to continue to grow as a result of the projected shortages of physicians and other health care professionals, the growing demand for care driven by an aging population, and the continuing strong PA applicant pool. Accordingly, The Bureau of Labor Statistics projects a 39% increase in the number of PA jobs between 2008 and 2018. With its relatively short training time and the flexibility of generalist-trained PAs, the PA profession is well positioned to help fill projected shortages in the numbers of health care professionals—if appropriate resources are available to support the education system behind them.

AREAS OF ACUTE NEED

Faculty Shortages

Faculty development is one of the PA professions critical needs, especially as we continue to foster the growing demand for an increased primary care workforce. The PA teaching profession faces large numbers of retirements in the next 10-15 years as nearly half of PA program faculty are 50 years or older. An interest in education must be developed early in the educational process to ensure a continuous stream of educators. Furthermore, the significant loan burdens that prevent many physician assistants from entering academia must be alleviated. In order to attract the most highly qualified faculty, PA education programs must have the resources to help clinicians transition into education, including curriculum development, teaching methods, and laboratory instruction. Without federal support, we will face an impending shortage of educators who are prepared for and committed to the critical teaching role that will ensure the next generation of skilled practitioners.

Clinical Site Shortages

Outside of the classroom, PA education faces additional challenges in meeting the demand for qualified and highly trained practitioners. A lack of clinical sites for PA education is hampering PA

Physician Assistant Education Association
655 K Street NW, Suite 700, Washington, DC 2001- 2385 Tel. (703) 548-5538
www.PAEAonline.org

programs' ability to produce PAs at the pace needed to meet the demand for primary care in the U.S. This shortage is caused by two main factors: a shortage of medical professionals (preceptors) willing to teach students as they are cycling through their clinical rotations, and a lack of sites with the physical space to teach. Cutbacks in federal and state funding of Area Health Education Centers (AHECs) has also contributed to reduced access to clinical training for PA students, particularly in rural and underserved communities. Federal funding can help incentivize practicing clinicians to both offer their time as preceptors, and volunteer their clinical operations as training grounds for interprofessional training opportunities with PAs and other members of the health professional.

Enhancing Diversity

The Physician Assistant Education Association is committed to enhancing the diversity of the PA education community, workforce diversity, and practice in underserved areas. It is increasingly important for patient care that the health workforce better represents America's changing demographics, as well as addresses the issues of disparities in health care. PA programs have been committed to attracting students from underrepresented minority groups and disadvantaged backgrounds into the profession, including veterans who have served our country and desire to transition to civilian health professions. Studies have found that health professionals from underserved areas are three to five times more likely to return to underserved areas to provide care. PA programs are looking for unique ways to recruit diverse individuals into the profession, and sustain them as leaders in the education field and within their communities. PAEA recognizes the need to recruit diverse faculty, as a diverse faculty pool with a broad perspective of experiences, enhances the educational setting and is beneficial to students. If we can provide resources to schools that are particularly poised to improve their diversity recruitment efforts and replicate or create best practices including transition programs for our veterans, we can begin to address this systemic need.

In order to leverage the efforts of PA programs through Title VII funding to increase workforce diversity in the PA profession, PAEA also supports funding for the Health Careers Opportunity Program (HCOP), and increased funding for the Scholarships for Disadvantaged Students and National Health Service Corps. These programs help to provide a clear path for students who might not otherwise consider a physician assistant career.

Title VII Funding

Title VII funding can serve as a solution and a remedy to many of the PA profession's areas of need, including faculty development, clinical site expansion and diversification of the primary care workforce. These funds enhance clinical training and education, assist PA programs with recruiting applicants from minority and disadvantaged backgrounds, and enable innovative programs that focus on educating a culturally competent workforce. Title VII funding increases the likelihood that PA students will practice in medically underserved communities with health professional shortages. The absence of this funding would result in the loss of care to patients with the most urgent needs.

Title VII support for PA programs was strengthened in 2010 when Congress enacted a 15 percent allocation in the appropriations process specifically for PA programs working to address the health provider shortage. This funding has enhanced capabilities to train future PAs, creatively expand care to the underserved, and develop a more diverse PA workforce:

- One Texas program has used its PA training grant to support the program at a site in an underserved area. This grant provides assistance to the program for recruiting, educating,

Physician Assistant Education Association
655 K Street NW, Suite 700, Washington, DC 2001- 2385 Tel. (703) 548-5538
www.PAEAonline.org

and training PA students in the largely Hispanic South Texas and mid-Texas/Mexico border areas and supports new faculty development.

- A New York program is using its PA training grant to operate a mobile health vehicle to provide health education and initial health screenings to local underserved communities. The direct exposure achieved by utilizing a mobile health vehicle provides the communities with medical and preventive education and health screenings while also addressing the students' awareness of cultural competency and health literacy. Equally as important, the experience has motivated students to specialize in primary care.
- A Virginia program uses its PA training grant to support transitioning veterans, while increasing the placement of graduates in primary care and medically underserved communities. The grant allows the PA program to provide scholarship to incoming physician assistant students who are veterans, and who dedicate the beginning of their careers to a primary care setting.

Recommendations on FY 2017 Funding

The Physician Assistant Education Association requests the Appropriations Committee's support in funding for Title VII health professions programs at a minimum of $280 million for FY 2017.This level of funding is crucial to support the nation's ability to produce and maintain highly skilled primary care practitioners, particularly those from diverse backgrounds and the military who will practice in medically underserved areas and serve vulnerable populations. We also ask for the continuation of the 15 percent allocation for PA education programs in the Primary Care cluster.

We thank the members of the subcommittee for their support of the health professions and look forward to your continued commitment to finding solutions to the nation's health workforce shortage.

Physician Assistant Education Association
655 K Street NW, Suite 700, Washington, DC 2001- 2385 Tel. (703) 548-5538
www.PAEAonline.org

Statement of Patricia de Stacy Harrison
President and CEO, Corporation for Public Broadcasting
Before the Subcommittee on Labor, Health and Human Services, Education and Related Agencies, House Committee on Appropriations
March 24, 2016

Chairman Cole, Ranking Member DeLauro, and distinguished members of the subcommittee, thank you for allowing me to submit this testimony on behalf of America's public media service—public television and public radio—on-air, online and in the community. The Corporation for Public Broadcasting (CPB) requests level funding of $445 million for Fiscal Year (FY) 2019, $50 million in FY 2017 for the replacement of the public broadcasting interconnection system, and $25.74 million for Ready To Learn at the Department of Education.

Nearly fifty years after passage of the Public Broadcasting Act, this uniquely American public-private partnership is keeping its promise—to provide high-quality trusted content that educates, inspires, informs and enriches. Through the nearly 1,500 locally owned and operated public radio and television stations across the country, public media reaches nearly 99 percent of the American people—with an overwhelming majority of them consuming public media throughout the year.

Every day more people, businesses, organizations and foundations are committing their time and resources to support the work of public media. President Ronald Reagan said, "government should provide the spark and the private sector should do the rest." The federal appropriation remains the critical investment that ensures your constituents have access to public media for free and commercial free. America's local public media stations utilize the "spark" of the federal investment—approximately 10 to 15 percent of a stations' budget—and raise the rest from non-federal resources.

Private donations and existing funding sources can and do help defray costs for the much-honored programs of public television and radio. In fact, non-federal funding represents five of every six dollars invested annually in public broadcasting. However, the federal investment is indispensable to sustaining the operations of public broadcasting stations, capitalizing on the benefits of an integrated system, and fostering the public service mission they pursue: community-based accountability and a universal service to which the Public Broadcasting Act aspires. Over the years, congressionally mandated studies have concluded that there is no alternative to federal funding when it comes to safeguarding the public media service that Americans know and love.

Our trusted, noncommercial services are especially important to those living in rural communities where the local public media station is sometimes the only source of broadcast news, information and educational programming. For these smaller stations serving rural, minority and other underserved communities, the federal dollars provide much more than just a spark, in some cases CPB's investment can represent as much as 40 percent of their budget.

Public media's contribution to education—from early childhood through adult learning—is well documented. We are America's largest classroom, with proven educational content available to

all children, including those who cannot afford preschool. Further, parents, caregivers and teachers repeatedly value public media content as the "most trusted."

CPB's work with the Department of Education's Ready To Learn program is an excellent example of how public media brings together high-quality educational content with on-the-ground work in local communities. More than twenty years ago, Congress recognized the reach and potential of public media to help disadvantaged children become better prepared to enter school. Last year, Congress reaffirmed this belief in the Every Student Succeeds Act by reauthorizing Ready To Learn. For the next five years, public media will continue to provide coordinated and connected STEM and literacy learning experiences for children across multiple platforms, including TV, Internet, mobile, and in multiple settings, including in classrooms, summer and after-school programs, and at home.

While innovation on multiple platforms is important, television is still the primary tool to reach low-income and rural families. More than 80 studies have proven that Ready To Learn content builds and improves early literacy skills for high-need children, ages two to eight. Continued funding will allow public media to carry-on this critical work.

Public media is also differentiated from commercial media through content that matters and engagement that counts. An example of this is CPB's "American Graduate" initiative, which puts faces behind the statistic of one million young people failing to graduate from high school every year. Our stations told the stories, and communities throughout the country responded. Over the past five years more than 120 public media stations located in at-risk communities in 49 states have worked with nearly 1,600 national and community-based partners to bring together diverse stakeholders and community organizations all working toward a national graduation rate of 90 percent by 2020. I are pleased to report that as a result of our and others combined efforts, in 2015, the high school graduation rate rose to 82 percent for the first time in our nation's history. However, much work remains and many stories remain untold.

Public media is utilizing today's technology to provide content of value to millions of Americans. CPB strategically focuses its investments through the lens of what we refer to as the "Three D's" —Digital, Diversity and Dialogue. This refers to support for innovation over multiple platforms; content that is for, by and about Americans of all backgrounds; and services that foster engagement between the American people and the public service media organizations that serve them.

Public media tells stories that are worth telling, worth watching and worth listening to. The Public Broadcasting Act ensures diversity in programming by requiring CPB to fund independent and minority producers. CPB fulfills this mission, in part, by funding the Independent Television Service, the five Minority Consortia entities in television (African American, Latino, Asian American, Native American and Pacific Islander), several public radio consortia (Latino Public Radio Consortia, African American Public Radio Stations, and Native Public Media) and numerous minority public radio stations. Moreover, CPB, through its Diversity and Innovation fund, makes direct investments in the development of diverse primetime and children's broadcast programs as well as innovative digital content.

What further distinguishes the power of public media is that our mission directs us to serve every American—not only on-air or online, but face to face in our communities. More than 70 percent of CPB's appropriation goes directly to local stations who work closely with their communities to best serve local interests and concerns. This allows public media to work in partnership with people of diverse backgrounds, ensuring that we are listening to and reflecting the changing story of America.

Facing the reality that many communities are losing local news coverage because of cutbacks in commercial journalism outlets, CPB is helping stations support the production of more local news content. Since 2009, CPB has invested more than $27 million to launch 22 local and regional newsroom collaborative operations. These partnerships connect 105 public media stations in 37 states, providing the basis for a vibrant multimedia network of high-quality journalism.

In the coming years, public media has an opportunity to help fill the widening substantive news gap left by weak local newspapers. CPB's goal is to support and encourage public media organizations and producers to operate as a true news network – one that routinely works together to strengthen both the signature national programs and the local/regional news, reaching more of the American people more often on more platforms with more compelling journalism.

The work of public media goes well beyond broadcast. Public television and radio stations are increasingly effective partners with state and local public safety, law enforcement and first responder organizations—connecting these agencies with one another, with the public, and with vital data-casting capabilities in times of crisis.

Further, CPB is supporting stations, both financially and by defining best practices, so they can create more public-private partnerships, bringing more services and benefits to their communities. One example of this local public-private partnership is CPB's Veterans Coming Home initiative. Stations and their partners are communicating veterans' stories through award winning reporting, documentaries, and online content; convening local events such as town hall meetings that connect veterans with resources; and collaborating with local veterans' organizations to identify services available to them.

Ever since the FCC set aside a block of spectrum exclusively for non-commercial educational use in 1953, public media has been efficiently utilizing this spectrum as a vehicle to serve families all across America. The FCC's upcoming spectrum incentive auction and subsequent repacking process present a unique set of challenges for public media.

Unlike commercial broadcast stations, where auction decisions will be made at the corporate level, public television stations are locally owned and operated, so each station will directly incur the costs of the auction and repacking process. Not all of these costs will be covered by auction proceeds, nor is it certain that the $1.75 billion that Congress has set aside for repacking will be sufficient. Indeed, many stations that do not participate in the auction will still have to spend time and resources on the mandatory repacking process.

Finally, it must be understood that CPB will not receive any auction proceeds. Further, public broadcasting license holders that participate in the auction are not required to invest their proceeds in a public media service. The auction brings an air of uncertainty to public television service both in terms of future signal coverage and financial impact. The continued federal investment will help safeguard this valued service for all Americans.

Interconnection

Interconnection is the backbone of the public broadcasting system, delivering content every day from public media producers to the locally owned and operated public television and radio stations in communities throughout the country. Without it, there is no nationwide public media service. Congress recognized the need for an interconnection system in 1967 when it passed the Public Broadcasting Act. It has always funded the interconnection system, and has provided a separate appropriation for interconnection since fiscal year 1991.

As we near the expiration of our current interconnection system for both television and radio, CPB must plan for the next generation of interconnection. Technology and distribution systems have greatly evolved since Congress established its practice of funding interconnection. Today, an expansive range of technologies, including satellite, cloud and terrestrial broadband, is widely available to create the most cost effective and efficient means to distribute content to public broadcasting stations. We are grateful for Congress's $40 million initial investment in the public broadcasting interconnection system in FY 2016 and would appreciate your continued support for this essential infrastructure.

Conclusion

Public media's treasure trove of content and services is available to all Americans for about $1.35 per American per year. As a result of the federal investment, public media stations are able to connect to people's lives in impactful ways—ensuring every child is ready to learn, every person has access to lifelong learning; every veteran can connect to resources and support; and every citizen has access to fact-based local, national and global journalism. We make the arts accessible to all Americans and provide emergency alert services for first responders. CPB ensures that 95 cents of every dollar it receives goes to support local stations and the programs and services they offer to their communities; no more than five cents of every dollar goes to the administration of funding programs and overhead.

CPB's FY 2019 request of $445 million and FY 2017 requests of $50 and $25.74 million for interconnection and Ready To Learn, respectively, balance the fiscal reality facing our nation with our statutory mandate to provide a valuable and trusted service to all Americans. Today, the challenges we face are more complex than ever and require attention to education, innovation, and collaboration.

Public media has been inspiring and enriching our lives for nearly half a century, and Congress' support of our request will allow stations to continue providing high-quality trusted content that educates, informs, and strengthens our civil society. Mr. Chairman and members of the subcommittee, this is only part of the story of America's public media system. Public media is truly a national treasure. I thank you for allowing me to submit this testimony and appreciate your consideration of our request for funding.

Written Statement for the Record by

Juan Quintana, DNP, MHS, CRNA
President, American Association of Nurse Anesthetists

Headquarters: 222 S. Prospect Ave., Park Ridge, Ill. 60068-4001, 847-692-7050
Washington: 25 Massachusetts Ave, NW, Suite 550, Washington, DC 20001, 202-484-8400

House Appropriations Subcommittee
On Labor, Health and Human Services, Education and Related Agencies
Washington, DC

March 24, 2016

FY 2017 Appropriations Request Summary

	FY15 Enacted	FY16 Enacted	AANA FY 17 Request
HHS / HRSA / BHPr Title 8 Advanced Education Nursing, Nurse Anesthetist Education Reserve	No report language	No report language	Report language supporting at least $5 mil for nurse anesthesia education
Total for Advanced Education Nursing, from Title 8	$63.581 mil	$64.581 mil	$66 mil for advanced education nursing
Title 8 HRSA BHPr Nursing Education Programs	$231.622 mil	$229.472 mil	$244 mil

About the American Association of Nurse Anesthetists (AANA) and Certified Registered Nurse Anesthetists (CRNAs)

The AANA is the professional association for more than 49,000 CRNAs and student nurse anesthetists, representing over 90 percent of the nurse anesthetists in the United States. Today, CRNAs deliver approximately 40 million anesthetics to patients each year in the U.S. CRNA services include administering the anesthetic, monitoring the patient's vital signs, staying with the patient throughout the surgery, and providing acute and chronic pain management

services. CRNAs provide anesthesia for a wide variety of surgical cases and in some states are the sole anesthesia providers in almost 100 percent of rural hospitals, affording these medical facilities obstetrical, surgical, and trauma stabilization, and pain management capabilities. CRNAs work in every setting in which anesthesia is delivered, including hospital surgical suites and obstetrical delivery rooms, ambulatory surgical centers (ASCs), pain management units and the offices of dentists, podiatrists and plastic surgeons.

Nurse anesthetists are experienced and highly trained anesthesia professionals whose record of patient safety is underscored by scientific research findings. The landmark Institute of Medicine report *To Err is Human* found in 2000 that anesthesia was 50 times safer then than in the 1980s. (Kohn L, Corrigan J, Donaldson M, ed. *To Err is Human.* Institute of Medicine, National Academy Press, Washington DC, 2000.) Though many studies have demonstrated the high quality of nurse anesthesia care, the results of a study published in *Health Affairs* in 2010 led researchers to recommend that costly and duplicative supervision requirements for CRNAs be eliminated. Examining Medicare records from 1999-2005, the study compared anesthesia outcomes in 14 states that opted-out of the Medicare physician supervision requirement for CRNAs with those that did not opt out. (To date, 17 states have opted-out.) The researchers found that anesthesia has continued to grow more safe in opt-out and non-opt-out states alike. (Dulisse B, Cromwell J. No Harm Found When Nurse Anesthetists Work Without Supervision By Physicians. *Health Aff.* 2010;29(8):1469-1475.)

CRNAs provide the lion's share of anesthesia care required by our U.S. Armed Forces through active duty and the reserves, staffing ships, remote U.S. military bases, and forward surgical

teams without physician anesthesiologist support. In addition, CRNAs predominate in rural and medically underserved areas, and where more Medicare patients live (Government Accountability Office. Medicare and private payment differences for anesthesia services. GAO-07-463, Washington DC, Jul. 27, 2007. http://www.gao.gov/products/GAO-07-463. (Liao CJ, Quraishi JA, Jordan, LM. Geographical Imbalance of Anesthesia Providers and its Impact on the Uninsured and Vulnerable Populations. *Nurs Econ.* 2015; 33(5):263-270.)

Importance of and Request for HRSA Title 8 Nurse Anesthesia Education Funding

Our profession's chief request of the Subcommittee is for $5 million to be reserved for nurse anesthesia education and $66 million for advanced education nursing from the HRSA Title 8 program, out of a total Title 8 budget of $244 million. We request that the Report accompanying the FY 2017 Labor-HHS-Education Appropriations bill include the following language: "Within the allocation, the Committee encourages HRSA to allocate funding of at least $5 million for nurse anesthetist education." This funding request is justified by the safety and value proposition of nurse anesthesia, and by anticipated growth in demand for CRNA services as baby boomers retire, become Medicare eligible, and require more healthcare services. In making this request, we associate ourselves with the request made by The Nursing Community with respect to Title 8 and the National Institute of Nursing Research (NINR) at the National Institutes of Health.

The Title 8 program, on which we will focus our testimony, is strongly supported by members of this Subcommittee in the past, and is an effective means to help address nurse anesthesia workforce demand. In expectation for dramatic growth in the number of U.S. retirees and their healthcare needs, funding the advanced education nursing program at $66 million is necessary to

meet the continuing demand for nursing faculty and other advanced education nursing services throughout the U.S. The program funds competitive grants that help enhance advanced nursing education and practice, and traineeships for individuals in advanced nursing education programs. It also targets resources toward increasing the number of providers in rural and underserved America and preparing providers at the master's and doctoral levels, thus increasing the supply of clinicians eligible to serve as nursing faculty, a critical need.

Demand remains high for CRNA workforce in clinical and educational settings, driven by an aging population requiring more care, and a growing percentage of surgical procedures requiring anesthesia being offered in outpatient settings. The supply of clinical providers has increased in recent years, stimulated by increases in the number of CRNAs trained. From 2006-2015, the annual number of nurse anesthesia educational program graduates increased from 1,900 to 2,468, according to the Council on Accreditation of Nurse Anesthesia Educational Programs (COA). The number of accredited nurse anesthesia educational programs grew from 105 to 115 during this time, and is currently 118. We anticipate increased demand for anesthesia services as the population ages, the number of clinical sites requiring anesthesia services grows, and a portion of the CRNA workforce retires.

The capacity of our nurse anesthesia educational programs to educate qualified applicants is limited by the number of faculty, the number and characteristics of clinical practice educational sites, and other factors – and they continue turning away hundreds of qualified applicants. A qualified applicant to a CRNA program is a bachelor's educated registered nurse who has spent at least one year serving in an acute care healthcare practice environment. They are prepared in

nurse anesthesia educational programs located all across the country, including Connecticut, Kentucky, Maryland, Mississippi, Missouri, New York, and Washington. To meet the nurse anesthesia workforce challenge, the capacity and number of CRNA schools must continue to grow and modernize with the latest advancements in simulation technology and distance learning consistent with improving educational quality and supplying demand for highly qualified providers. With the help of competitively awarded grants supported by Title 8 funding, the nurse anesthesia profession is making significant progress, but more is required.

This progress is extremely cost-effective from the standpoint of federal funding. Anesthesia can be provided by nurse anesthetists, physician anesthesiologists, or by CRNAs and anesthesiologists working together. Of these, the nurse anesthesia practice model is by far the most cost-effective, and ensures patient safety. (Hogan P et al. Cost effectiveness analysis of anesthesia providers. *Nursing Economic$*, Vol. 28 No. 3, May-June 2010, p. 159 et seq.) Nurse anesthesia education represents a significant educational cost-benefit for competitively awarded federal funding in support of CRNA educational programs.

# # #

UNITED TRIBES TECHNICAL COLLEGE
3315 University Drive, Bismarck, North Dakota 58504
Leander "Russ" McDonald, PhD, President, president@uttc.edu; 701-255-3285

FY 2017 Department of Education Appropriations:
Carl Perkins Act (Tribally Controlled Postsecondary Career and Technical Institutions); Strengthening Institutions (Title III-A, Sec. 316); Pell Grants

Submitted to the House and the Senate Appropriations Subcommittees on Labor-HHS-Education

March 31, 2016

United Tribes Technical College (UTTC) has for 47 years, and with the most basic of funding, provided postsecondary career and technical education and family services to some of the most impoverished high risk Indian students from throughout the Nation. Despite such challenges we have consistently had excellent retention and placement rates and are fully accredited by the Higher Learning Commission. We are proud to be preparing our students to participate in the energy economy in North Dakota and to be part of building a strong middle class in Indian Country by training the next generation of law enforcement officers, educators, medical providers, and administrators. We are governed by the five tribes located wholly or in part in North Dakota. *We are not part of the North Dakota University System and do not have a tax base or state-appropriated funds on which to rely.* The funding requests of the UTTC Board for FY 2017 are:

- *$10 million for base funding authorized under Section 117 of the Carl Perkins Act* for the Tribally Controlled Postsecondary Career and Technical Institutions program. This is $1.7 million above the FY 2016 level. These funds are awarded competitively and distributed via formula. We are seeking a change to the formula that is not so reliant on Indian Student Count in order to avoid dramatic swings in annual awards.

- *$30 million in discretionary funds as requested by the American Indian Higher Education Consortium for Title III-A (Section 316) of the Higher Education Act*, $2.4 million above the FY 2016 level.

- *Support the scheduled proposed $1.8 billion increase in the Pell Grant program and the reinstatement of Year-Round Pell Grant eligibility.*

Section 117 Perkins Funding –Tribally Controlled Career and Technical Institutions. We appreciate the $500,000 increase for Section 117 Perkins in FY 2016. This funding level finally brought Section 117 Perkins back to its FY 2012 pre-sequestration level. Funding for other programs authorized under the Perkins Act was restored several years ago. Perhaps Section 117 was overlooked as a source of career readiness and job training because it had been moved to the Higher Education portion of the budget, rather than staying in the Career and Technical Education account. We all realize the urgent need to better prepare a workforce to meet industry

and other emerging needs. We are part of that undertaking, but need more resources to come closer to our potential.

Acquisition of additional base funding is critical. We struggle to maintain course offerings and services to adequately provide educational services at the same level as our state counterparts. Perkins funds are central to the viability of our core postsecondary 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 relatively recent updates of our curricula to meet job market needs. Indeed, the ramifications of the North Dakota Bakken oil boom are apparent as we have seen faculty and students leave education in pursuit of jobs in the Bakken region. At the certificate level, UTTC recognized the need for more certified welders and heavy equipment operators in relation to the oil boom and expanded these programs in response to the workforce need. UTTC is now the only welding test site in a multi-state region approved by the American Welding Society. The hospital facilities in the regions were unable to hire certified Medical Coding & Billing personnel so we developed and currently offer this certificate as one of our online offerings. We are now able to train students for good paying in-demand employment with a focus on career rather than just a job. Lastly, we recently received Higher Learning Commission approval to offer a Bachelor's Degree in Environmental Science that will provide experiential research opportunities for our students.

Funding for United Tribes Technical College is a good investment. We have:

- Renewed unrestricted accreditation from the Higher Learning Commission for July 2011 through 2021, with authority to offer all of our full programs on-line. We offer 16 Associate degrees, 5 Certificates, and 3 Bachelor degree programs of study (Criminal Justice; Elementary Education; Business Administration). Six of the programs are offered online.
- Services including a Child Development Center, family literacy program, wellness center, area transportation, K-6 elementary school, tutoring, counseling, family and single student housing, and campus security.
- A projected return on federal investment of 20-1 (2005 study).
- A semester retention rate of 58% and a graduate placement rate of 82%.
- Students from 37 tribes represented at UTTC.
- Our students are very low income, and 67% of our undergraduate students receive Pell Grants.
- An unduplicated count of 536 undergraduate degree-seeking students: 828 continuing education students; and 24 dual credit enrollment students for a total of 1,283 students for 2014-2015.
- A dual-enrollment program targeting junior and senior high school students, providing them an introduction to college life and offering high school and college credits.

- A critical role in the regional economy. Our presence brings at least $34 million annually to the economy of the Bismarck region. A North Dakota State University study reports that the five tribal colleges in North Dakota made a direct and secondary economic contribution to the state of $181,933,000 in 2012.

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 American Indian Higher Education Consortium's request of $30 million for discretionary funding, $2.4 million above FY 2016. This is in addition to the $30 million in (Part F) mandatory funding. While these are not operational funds, they are critical for developmental activities and provide an opportunity for a modest amount of construction funding. Funds are distributed via a formula with up to 30 percent of funds authorized to be set-aside for competitive funding for facility construction and maintenance. We share with the other tribal colleges serious issues of inadequate physical infrastructure.

We are constantly in need of additional student housing, including family housing. Some of our students have to utilize private housing in Bismarck, and an offshoot of the oil boom in North Dakota is that housing prices have gone sky high. A two bedroom apartment in Bismarck rents for $1,200-$1,400 per month. With the completion of a Science, Math and Technology building on our South Campus on land acquired with a private grant, we urgently need housing for up to 150 students, many of whom have families. While we have constructed three housing facilities using a variety of sources in the past 20 years, approximately 50 percent of students are housed in the 100-year-old buildings of what was Fort Abraham Lincoln, as well as housing that was donated by the federal government along with the land and Fort buildings in 1973. These buildings require major rehabilitation. New buildings are actually cheaper than rehabilitating the old buildings that now house students.

Title III funds provide much needed support to strengthened academic offerings. Specifically, Title III has been instrumental in the College's efforts to provide baccalaureate programs, online Associate programs, and increase the technology infrastructure necessary to support student learning and campus management functions. Professional development activities has been supported by Title III, increasing the intellectual and technical capacity of faculty and staff. Additional activities carried out with support of Title III funding have been associated with increasing the College's Institutional Resources capabilities in order to strengthen relationships with alumni and forming relationships with organizations and individuals who may become supporters of the College. With the current Title III award, the College is anticipating expanding academic offerings through the development of a Master's level program. The support of Title III will be critical for attaining accreditation approval, program development, and acquiring highly qualified faculty.

Pell Grants. We support the proposed $30 billion for the Pell Grant program (a $1.8 billion increase), including the proposal to reinstate year-round Pell Grant eligibility, thus allowing students the opportunity to earn a third semester of Pell Grant funding during an academic year if they have already completed a full-time course load of 24 credit hours. As noted above, 67 percent of our undergraduate students receive Pell Grants. This resource makes all the difference in whether many of our students can attend college.

The Duplication or Overlapping Issue. As you know in March 2011, the Government Accountability Office issued two reports regarding federal programs which may have similar or overlapping services or objectives (GAO-11-474R and GAO-11-318SP). Funding from the Bureau of Indian Education and the Department of Education's Carl Perkins Act for Tribally Controlled Postsecondary Career and Technical Education were among the programs listed in the reports. *The full GAO report did not recommend defunding these programs; rather, it posed the possibility of consolidation of these programs to save administrative costs.* We are not in disagreement about possible consolidation of our funding sources, as long as program funds are not cut.

The Perkins funds supplement, but do not duplicate, the BIE funds. *Both sources of funding are necessary to the frugal maintenance of our institution.* We actively seek alternative funding to assist with academic programming, deferred maintenance, and scholarship assistance, among other things. The need for career and technical education in Indian Country is so great and the funding so small that there is little chance for duplicative funding. United Tribes Technical College and Navajo Technical University, who focus on career and technical education, received combined only $15.1 million in FY 2016 federal operational funds ($8.2 million from Perkins; $6.9 million from the BIE). That is not an excessive amount for two campus-based institutions who offer a broad array of programs geared toward the educational and cultural needs of their students and who teach job-producing skills.

We invite the Chair, Ranking Member and all members of this Subcommittee to visit United Tribes Technical College – we are in close proximity to the Bismarck airport. We would be honored and pleased to arrange such a visit.

Thank you for your consideration of our requests.

# # #

COUNCIL ON SOCIAL WORK EDUCATION
STRENGTHENING THE PROFESSION OF SOCIAL WORK
Leadership in Research, Career Advancement, and Education
1701 Duke Street, Suite 200, Alexandria, VA 22314 TEL 703.683.8080 FAX 703.683.8099 www.cswe.org

Testimony for Fiscal Year 2017

Department of Health and Human Services and Department of Education Funded Programs

Submitted to the Subcommittee on Labor, Health and Human Services, Education, and Related Agencies; Committee on Appropriations; United States House of Representatives

March 29, 2016

Submitted by

Dr. Darla Spence Coffey, President, Council on Social Work Education

Phone: (703) 683-8080; E-mail: DCoffey@cswe.org

On behalf of the Council on Social Work Education (CSWE), I am pleased to offer this written testimony to the House 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 750 baccalaureate and master's programs of professional social work education. CSWE requests:

Agency	Account	Program	Funding Requested
HHS	HRSA	Title VII Health Professions Programs	$280 Million
HHS	HRSA	Title VII Mental and Behavioral Health Education and Training Program	$1 million for the Leadership in Public Health Social Work Education (LPHSWE) Program
HHS	HRSA	HRSA Behavioral Health Workforce Education and Training Grant Program	$56 Million
HHS	SAMHSA	Minority Fellowship Program	$11.7 million, including at least $6.4 million for MFP core activities
ED	N/A	Pell Grant	$5,935 for the maximum Pell Grant
ED	N/A	GAANN	$31 million
ED	N/A	Loan Repayment Programs	Support without a cap on repayment
HHS	NIH	Overall Funding for NIH	$34.5 billion

HRSA Title VII Health Professions Programs

CSWE urges the Committee to provide $280 million in FY 2017 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 health professions programs are designed to provide health-care providers with interdisciplinary training to meet the health-care needs of all Americans, including the underserved and those with special needs, and to expand minority representation in the health-care workforce. Social workers and social work students are eligible for Title VII programs, which provide loans, loan guarantees, and scholarships to students, and grants to institutions of higher education and non-profit organizations to build and maintain a robust health-care workforce.

CSWE urges the Committee to provide $1 million for the Leadership in Public Health Social Work Education (LPHSWE). This funding supports the next generation of public health and social workers and ensures critical leadership, resources, and training.

HRSA Behavioral Health Workforce Education and Training Program (BHWET)

The BHWET Program builds on HRSA's mental and behavioral health training efforts by providing grant funding for the mental health and substance abuse workforce serving children, adolescents, and transitional-age youth at risk for developing, or who have developed, a recognized behavioral health disorder.[1] In 2015, the program's first year, social work programs were awarded about $19,087,780 serving an estimated 4,196 students. **CSWE urges the Committee to support $56 million for the BHWET Grant Program**, the level provided in the President's budget request. This is a $6 million increase above the FY 2016 enacted level. CSWE

[1] http://www.integration.samhsa.gov/integrated-care-models/safety_net_providers

also encourages the Committee to include language specifying that accredited master's-level schools and programs of social work must be CSWE-accredited to receive funding. Similar criteria have been placed on mental and behavioral health grants at HRSA.

SAMHSA Minority Fellowship Program

CSWE urges the Committee to appropriate the highest level possible for the SAMHSA Minority Fellowship Program (MFP) in FY 2017. The goal of the MFP program is to increase the number of minority doctoral students preparing for leadership roles in mental health and substance use fields.[2] CSWE is one of six grantees of this critical program and administers funds to exceptional minority doctoral social work students. In addition, CSWE also administers funds for the Minority Fellowship Program-Youth (MFP-Y). This program reduces health disparities and improves behavioral health-care outcomes for racially and ethnically diverse populations by increasing the number of culturally competent master's-level behavioral health professionals serving children, adolescents, and populations in transition to adulthood.

Since its inception in 1974, the MFP has helped support doctoral-level professional education for over 1,000 ethnic minority social workers, psychiatrists, psychologists, psychiatric nurses, and family and marriage therapists. Still, the program struggles to keep up with the demands on these health professions. **The President's FY 2017 budget request includes $11,669,000 to support six MFPs, two MFP-Y, two MFP-AC grants, and three technical assistance and evaluation support contracts. CSWE urges the Committee to support this request, including at least $6.4 million for MFP core activities.**

[2] According to SAMHSA, minorities make up over one-fourth of the population, but less than 20 percent of behavioral health providers come from ethnic minority communities. Retrieved from SAMHSA Minority Fellowship Program, http://www.samhsa.gov/minorityfellowship/.

Department of Education (ED): Student Aid Programs

CSWE supports full funding to bring the maximum individual Pell Grant to $5,935 in FY 2017. Pell Grants are one of the most important programs to increase access and affordability to ensure that all students, regardless of economic circumstances, can pursue higher education.

The Graduate Assistance in Areas of National Need (GAANN) program provides graduate traineeships in critical fields of study. Currently, social work is not defined as an area of national need; however, it was recognized by Congress as one in the Higher Education Opportunity Act of 2008. **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 the Subcommittee to provide the FY 2012 pre-sequester funding level of $31 million for the GAANN Program and include social work as an area of national need.**

CSWE supports ED's efforts to help students with high debt loads serve in low paying positions. Income-driven repayment and Public Service Loan Forgiveness programs enable social work graduates to serve in high-needs communities. **CSWE urges the Subcommittee to support loan repayment programs without a cap on loan forgiveness.**

National Institutes of Health: Support For Research

CSWE supports at least $34.5 billion for NIH in FY 2017 and advocates for 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, and racial-, ethnic-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.

Subcommittee on Labor, Health & Human Services, Education & Related Agencies
Outside Witness Testimony
Fiscal Year 2017 Appropriations

Thank you for the opportunity to submit testimony regarding the National Institute of Health (NIH) 2017 budget request. My name is Donna Carmical, I am the grandmother of a child who died from pediatric cancer. We lived in blissful ignorance about childhood cancer before Declan was diagnosed. We assumed, like most Americans, that our country was doing everything imaginable to ensure that children would have the most advanced cures and treatments possible. We were wrong, horribly wrong. The National Institute of Health (NIH) is unfairly discriminating against children -- the children who have battled cancer, who are battling cancer as well as the children yet to be diagnosed – and doing children a grave injustice. NIH has called childhood cancer "rare" not really a problem and said they could do more if Congress provided more funding. Childhood cancer research is not a priority for NIH.

Despite the fact that Senate report language has urged NIH to increase funding for childhood cancer research in a variety of statements over the past decade, NIH has barely acknowledged this problem. It is hard to understand their rationale. Some compelling facts:

- Childhood cancer is the #1 disease related killer of kids in the U.S., killing thousands of children each and every year
- The incidence of childhood cancer has been increasing steadily over the past decades. Today 1 in 285 children will be diagnosed with cancer before they reach the age of 20
- 20% of children diagnosed are terminal on diagnosis
- 60% of children diagnosed suffer life altering impacts of treatments, largely due to the lack of pediatric protocols, treatments are often a guess game of experiments and use of downsized adult protocols
- 95% of the survivors of childhood cancer will suffer serious health impacts before they reach the age of 45
- Adult cancers and childhood cancers are different, while childhood cancer research often benefits adults with cancer the opposite is less common.

Childhood cancer is not one disease, there are 16 major types of cancer and over 100 subtypes. Many of these childhood cancers, like DIPG, AT/RT, receive little to no funding for research. The National Cancer Institute indicates that survival rates for a few childhood cancers like acute lymphoblastic leukemia (ALL) have improved dramatically over the past decades, ironically this is due to the investment in research. NIH makes little mention of statistics regarding the deadly childhood cancers where there has been little to no research for decades.

There are many urgent reasons to invest in childhood cancer research yet NIH persists in ignoring this issue at great peril to our children and their children. At last year's Senate hearing, I listened to Dr. Fauci state that NIH spends more than $3 billion a year trying to cure AIDs. As one Senator said, if you take your medicine, AIDS is not killing anyone in this country. Dr. Fauci stated that $6 Billion a year would be saved by curing AIDS. Thousands of children are dying each year as a result of childhood cancer, and tens of thousands of survivors are irreparably harmed largely because we have done so little to develop pediatric cancer treatments and protocols. A cost analysis about the realities of childhood cancer should be done by NIH. Considering that 16,000 children under the age of 19 are diagnosed each year, one could speculate that curing childhood cancer could save more than $8 Billion a year.

Subcommittee on Labor, Health & Human Services, Education & Related Agencies
Outside Witness Testimony
Fiscal Year 2017 Appropriations

The average age of a child diagnosed with cancer is 8 years old, the long term costs of 380 thousand survivors who have been treated with less than the best treatments has a long term cost to society that hasn't been calculated. If survivors pass the 5 year survival rate -- they are statistically considered cured; yet, many children suffer long term impacts, secondary cancers, heart problems, infertility, learning disabilities, stunted growth, hearing problems and more. The increase in survivors, burden of disease, growing number of survivors, as well as number of deaths each year are a great cost to society. An investment in childhood cancer research could deliver big results -- pediatric protocols that might result in cures, less invasive treatments, reduction in life altering impacts, etc.

Congress required the Government Accounting Office to review how NIH sets priorities and review the strategic planning process a few years ago, GAO Report 14-246. The Senate required NIH to submit an overarching strategic plan by December 2015. The manner in which NIH sets priorities, how they make decisions that will result in the best outcomes for the American people is difficult to understand and like their budget process less than transparent. The strategic planning process requires that NIH consult internally and externally, that they consult with Congress, stakeholders and the public. Despite stakeholder requests to be part of the strategic planning effort, there was no real outreach to make this happen. The Strategic Plan recently completed does not really comport with the intent of the legislation. The NIH Strategic Plan does not give the public a sense of its four year long range strategic goals, short range agency priorities and in fact mostly expands the mission statement. There is no real sense in terms of what kind of results and outcomes the public should expect in terms of a $120 Billion investment. However, NIH strategic plan objectives could all benefit by significant investment in childhood cancer research (advance opportunities in biomedical research, foster innovation by setting NIH priorities, enhance scientific stewardship, excel as a Federal science agency by managing for results).

NIH has a less than transparent budget process, the RCDC indicates that approximately $6Billion is dedicated to research in the following areas: AIDS, Drug Abuse, Obesity, Tobacco and Alcoholism (recognizing that it is difficult to understand the RCDC portfolio as there is lots of double counting). As a taxpayer and investor in the NIH portfolio the childhood cancer community would like to see NIH re-prioritize their research and find significant investment in childhood cancer research as well as a childhood cancer research line item in their budget. This means investment in research, not more studies but research grants that will result in real research towards finding less invasive treatments for kids and specific childhood cancer drugs, treatments and cures. This is not a matter of more money for NIH, it's a matter of priorities and childhood cancer research should be a national priority. Our kids deserve no less. We need specific childhood cancer research, not more studies and administrative costs.

As reported by *The Atlantic* in a January 2013 article, "*there is not enough funding for childhood cancer, specifically. The National Cancer Institute, a government organization, provides funding for researchers, but only 10 percent of them can move forward with their findings due to budget cuts. Most of the financial support researchers receive is from philanthropists. In the meantime, research that could benefit children on an individual level stays in the lab, and doctors prescribe the same regimens that can be successful, but can also hurt the patient in several ways.*

Subcommittee on Labor, Health & Human Services, Education & Related Agencies
Outside Witness Testimony
Fiscal Year 2017 Appropriations

Researchers say they are working hard to discover new theories and treatments, but they feel they are being held back." The article goes on to quote, Dr. William Carroll, researcher and director of the cancer institute at New York University saying, *"Ninety-six percent of grants (sic childhood cancer) don't get funded ... There's no doubt there's less funding available, and it's driving people out of the field."*

Ironically many pediatric cancer organizations raising funds for childhood cancer research have been started by families who have lost a child to pediatric cancer. These families are trying to fund research because their eyes have been opened to the lack of childhood cancer research funding, they have seen their children suffer and die and they want to create awareness and change this picture for kids. Families desperately want other kids to have cures denied to their own children. The thing is that all the money we can raise by shaving heads, selling lemonade, golf tournaments, car washes, races, bake sales – all of this will not make a dent in this problem. Even the largest organizations that are raising tens of millions of dollars means that cures for children are probably 100 years into the future. Our children need significant Federal investment in childhood cancer research now. Childhood cancer research needs a huge investment, an investment of billions – the kind of investment we have made in AIDS research, EBOLA, etc, the kind of research that will ensure results.

Dr. Collins says we should envision the first AIDS free generation since the virus emerged more than 30 years ago. This success would not have been possible without the substantial investment of dollars in AIDS research, an investment of tens of billions of taxpayer dollars over the last two decades. NIH is seeking a cure, a vaccine and that is great but only around 20% of that $3 billion annually is being used to develop a cure for AIDS. It is time to re-prioritize those programs and as required by law determine where dollars will achieve the most in terms of results and "manage for results" as stated in the NIH strategic plan.

Congress has urged NIH to deal with the issue, the Children's Health Act (CHA) of 2000 required NIH to study risk factors for childhood cancer and improve outcomes for children with cancer; it required NIH to conduct and support research directly related to disease in children; to insure investment in tomorrow's pediatric research. It's hard to understand how these requirements have been carried out – where are the results of this requirement. The National Children's Study was passed in 2002, Congress appropriated over $1 billion to this debacle with little to show for these funds, where is the accountability. It is also mind-boggling that this 15 year journey to put together a cohort of 1000,000 children failed at great cost to the taxpayer and it appears not even the remnants of this study will factor into the newly funded Precision Medicine Initiative. As taxpayers and investors in the country's largest research organization, the public deserves accountability, transparency and answers in how NIH sets priorities and why childhood cancer research is continually ignored in the funding process. It seems the statistical answer is that annually 1.6 million adults are diagnosed with cancer and only around 16,000 children; but, numbers can be used to tell the story you want. If you consider that 77% of those 1.6 million adults are over the age of 55, grandparents like me, most of us would tell you that we think childhood cancer research should be a priority in funding decisions! Our grandchildren deserve the best that we can give them, not what's left over.

Subcommittee on Labor, Health & Human Services, Education & Related Agencies
Outside Witness Testimony
Fiscal Year 2017 Appropriations

What we learned during Declan's battle has left us forever changed. What we saw and learned during those many months in the hospital is life altering. What we see every single day, what these brave kids, these babies endure -- you have to see the horror to understand where the childhood cancer community is coming from. Watching our kids being treated with experimental protocols – knowing there are no cures that the poison, cut and burn techniques are used because this is all our medical community has -- it is wrong. The medical community trying to save our kids deserves better treatment options and drugs that will only come through research.

I'm nobody special, just a mother and grandmother. I understand that I don't know much compared to the wonderful scientists at NIH. I understand that the budget process is hard work for the committees, and resources are limited. But my experience over the past 5 years compels me to fight for kids. I can't do anything to change what happened to our sweet Declan, but I believe research will result in more funding for those deadly childhood cancers. Much like the prognosis has changed for AIDS over the past decades, I believe research could provide pediatric treatments and protocols that will offer cures to children like Declan in the future. We can't keep condemning these kids to death year after year and do nothing because of money.

I hope you will investigate and legislate more about the childhood cancer issue. Making childhood cancer research a priority in the Federal budget process would be a tremendous legacy for Congress and has great potential to give children the cures and hope they deserve. Thank you.

THE ASKS FOR NIH BUDGET

1. **Transparency** – meet the requirement of GPRA by providing a strategic plan, annual plan, annual performance report on performance.gov. Eliminate double counting in the RCDC information.
2. **Burden of Disease Study** – require NIH to contract out a burden of disease study that considers all aspects of childhood cancer costs to society, annually and over time.
3. **Childhood Cancer Research** – legislate an appropriation floor for funding that should go directly into childhood cancer research grants in keeping with the Children's Health Act of 2000
4. **Line Item** – Require that NIH develop a funding line item for childhood cancer research. This creates transparency and accountability in the budget process.

Testimony of the American Academy of Pediatrics Concerning Fiscal Year 2017 Appropriations for Programs in CDC, HRSA, and Office of Population Affairs

Submitted for the Record to the House Appropriations Subcommittee on Labor, Health and Human Services, Education and Related Agencies

April 15, 2016

Submitted by: Benard P. Dreyer, MD, FAAP, President of the American Academy of Pediatrics

The American Academy of Pediatrics (AAP), a non-profit professional organization of 64,000 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 2017 and beyond. AAP urges all Members of Congress to put children first when considering short and long-term federal spending decisions.

As pediatricians, we not only diagnose and treat our patients, we also promote preventive interventions to improve overall health. Likewise, as policymakers, you have an integral role in ensuring the health of future generations through adequate and sustained funding of vital federal programs. As such, we urge you to pass strong policies that invest in children in the earliest days of life. We implore you to take meaningful strides to address chronic poverty and its impacts on the health and well-being of American families.

AAP supports robust funding of the Department of Health and Human Services (HHS) and its individual agencies which all combine to support important programs that ensure the health and safety of children. Federal funding through these agencies supports critical programs that address pressing public health challenges including: efforts to prevent infant mortality and birth defects; healthy child development; antimicrobial resistance and infectious diseases; emergency medical services for children; mental health and substance abuse prevention; tobacco prevention and cessation; unintentional injury and violence prevention; child maltreatment prevention; childhood obesity; environmental and chemical exposures; poison control; teen pregnancy prevention and family planning; health promotion in schools; and medical research and innovation. In addition, we would like to highlight our support for investments in the following crucial child health programs:

National Center for Birth Defects and Developmental Disabilities (CDC)

The National Center for Birth Defects and Developmental Disabilities (NCBDDD) is a center within CDC that seeks to promote the health of babies, children, and adults and enhance the potential for full, productive living. According to the CDC, birth defects affect 1 in 33 babies and are a leading cause of infant death in the United States. The center has done tremendous work in the way of identifying the causes of birth defects and developmental disabilities, helping children to develop and reach their full potential, and promoting health and well-being among people of all ages with disabilities. The center also conducts important research on fetal alcohol syndrome, infant health, autism, congenital heart defects, and other conditions like Tourette Syndrome, Fragile X, Spina Bifida and Hemophilia. NCBDDD has proven to be an asset to children and their families and supports extramural research in every State.

FY 2017 Request: $135.610 million; FY 2016 Level: $135.610 million.

Emergency Medical Services for Children (HRSA)
Established by Congress in 1984 and last reauthorized in 2015, the Emergency Medical Services for Children (EMSC) Program is the only federal program that focuses specifically on improving the pediatric components of the emergency medical services (EMS) system. EMSC aims to ensure that state of the art emergency medical care for the ill and injured child or adolescent pediatric services are well integrated into an EMS system backed by optimal resources; and the entire spectrum of emergency services is provided to children and adolescents no matter where they live, attend school, or travel. Gaps in providing quality care to children in emergencies continue to persist throughout the country. The EMSC program helps to address these gaps by promoting the quality of care provided in the pre-hospital and hospital setting, reducing pediatric mortalities due to serious injury, and supporting rigorous multi-site clinical trials through the Pediatric Emergency Care Applied Research Network (PECARN).

FY 2017 Request: $21.213 million; FY 2016 Level: $20.162 million.

National Vaccine Injury Compensation Program (HRSA)
The National Vaccine Injury Compensation Program (NVICP) was established in 1988 to ensure an adequate supply of vaccines, stabilize vaccine costs, and establish and maintain an accessible and efficient forum for individuals found to be injured by certain vaccines. NVICP is an alternative to the traditional tort system for resolving vaccine injury claims and provides compensation to individuals found to have been injured by certain vaccines. Over the past 5 years, NVICP has seen a 71.6% rise in the number of petitions filed, due in large part to the flu vaccine. In fact, more than 60 percent of all petitions filed are now adult claims for alleged injuries from the flu vaccine. Though the number of petitions has risen, the number of staff has not. This additional funding can be used to hire more staff in order to expedite the processing of claims, thereby reducing the administrative backlog.

FY 2017 Request: $9.2 million; FY 2016 Level: $7.5 million.

Lead Poisoning Prevention Program (CDC)
There is no safe level of lead exposure, and lead damage can be permanent and irreversible, leading to increased likelihood for behavior problems, attention deficit and reading disabilities, and failure to graduate high school, in addition to experiencing a host of other impairments to their developing cardiovascular, immune, and endocrine systems. Today, over 500,000 children are exposed to unacceptably high levels of lead, and prevention efforts are critical to protect children from its harmful effects. The crisis in Flint, MI is a tragic inflection point in the ongoing issue of vulnerable communities facing lead exposure as one of many forms of adversity, with lifelong health effects. Prevention efforts like those at CDC are critical to addressing this problem.

FY 2017 Request: $35 million; FY 2016 Level: $17 million.

Global Immunizations (CDC)

The U.S. government has played a leading role in expanding access to immunizations around the world. Since 1988, a coordinated global immunization campaign has reduced the number of

polio cases by more than 99 percent, saving more than 13 million children from paralysis and bringing the disease close to eradication. Investments in polio have also trained health workers and strengthened the surveillance systems, laboratory networks and biocontainment capabilities that helped to arrest the spread of Ebola in countries such as Nigeria and Uganda. Global mortality attributed to measles, one of the top five diseases killing children, declined by 79 percent between 2000 and 2014 thanks to expanded immunization, saving an estimated 17.1 million lives. Despite this progress, the world is failing to meet most of its immunization goals, due in large part to weak healthcare systems and challenges presented by migration, rapid urbanization, conflict and natural disasters. The U.S. government has a timely opportunity to foster interagency coordination for efficiency and impact and reprioritize global immunization targets, as outlined in the Global Vaccine Action Plan, through its updates of the U.S. National Vaccine Plan and the Centers for Disease Control and Prevention's (CDC's) Global Immunization Strategic Framework. The CDC should also maintain its support for country-level polio transition plans that are led by national governments and involve a broad range of stakeholders, which will be critical to ensuring continued benefits from past investments in the their routine immunization systems.

FY 2017 Request: $224 million; FY 2016 Level: $219 million.

Title X Family Planning Program (Office of Population Affairs)

Title X remains the sole source of dedicated federal funding for family planning services for underserved populations. In fact, 91 percent of clients had incomes at or below 250 percent of the federal poverty level. Through Title X health centers, nearly five million women and men access life-saving health care such as birth control, cancer screenings, and testing for sexually transmitted infections. In addition, Title X family planning centers help to avert an estimated one million unintended pregnancies.

FY 2017 Request: $327 million; FY 2016 Level: $286 million.

Children's Hospital Graduate Medical Education (HRSA)

The Children's Hospital Graduate Medicaid Education (CHGME) program is an essential investment in our children's health care – in promoting prevention and primary care, expanding health care for vulnerable and underserved children, and ensuring access to care for all children. Continued funding is essential to maintaining the gains that have been achieved under CHGME in strengthening the pediatric workforce pipeline. While much has been achieved, much remains to be done, as serious shortages in many pediatric specialties persist. Since Congress created the program in 1999 to address the gap in federal support for pediatric training, CHGME has increased the number of pediatric providers, addressed critical shortages in pediatric specialty care and improved children's access to care. Today, nearly half (49 percent) of all pediatric residents are trained by CHGME recipient hospitals. Overall, 51 percent of pediatric specialists are trained at CHGME hospitals, and in many specialties, such as pediatric surgery or critical care medicine, over 65 percent of physicians are trained at these children's hospitals.

FY 2017 Request: $300 million; FY 2016 Level: $295 million.

Gun Violence Prevention (CDC)

Gun violence is a serious public health issue, and the dearth of research on how best to prevent related morbidity and mortality makes it difficult to implement a public health approach to addressing this public health problem. The AAP supports funding to research how gun violence affects children, and believes that more research into this matter will allow for pediatricians and others who care for children to better understand how to protect children from these injuries and deaths.

FY 2017 Request: $10 million; FY 2016 Level: N/A.

Ryan White HIV/AIDS Program Part D (HRSA)

Part D of the Ryan White Program provides family-centered, primary medical care to women, infants, children, and youth living with HIV/AIDS throughout the US when payments for such services are unavailable from other sources. Part D improves access to primary HIV medical care through coordinated, comprehensive, culturally, and linguistically competent services. More than 90,000 women, infants, children, youth and family members access Ryan White Part D funded program services each year. In 2014, Part D provided funding to 114 community-based organizations, safety net and university hospitals and health departments in 39 states and Puerto Rico. We oppose the President's budget proposal to consolidate funds from Parts C and D of the Ryan White Program. Ryan White Part D is the lifeline for women, infants, children, and youth living with HIV/AIDS, and has proved instrumental in preventing mother-to-child transmission of HIV.

FY 2017 Request: $75.08 million (and no consolidation of Parts C and D); FY 2016 Level: $75.08 million.

America's children deserve better

Twenty percent of children in the United States now live in poverty – up from 17 percent in 2007. During this same time period many families in the United States have seen their savings depleted and one or both parents lose their jobs. Although the country's economic position is improving, such challenging economic conditions have impacted one group of Americans particularly hard: our children. Many children suffer from food insecurity, unstable housing, family dysfunction, abuse and neglect. Such adverse childhood experiences are linked with "toxic stress," a biologic phenomenon associated with profound and irreversible changes in brain anatomy and chemistry that have been implicated in the development of health-threatening behaviors and medical complications later in life including drug use, obesity, and altered immune function. Adults affected by such adverse childhood experiences are more likely to have experienced school failure, gang membership, unemployment, violent crime, and incarceration.

Children's health care is not the cost driver of overall health care spending

The United States continues to spend less on our children's health, education, and general welfare than most other developed nations in the world. Children under age 18 represent 30 percent of the total U.S. population, yet health care services for infants, children, and young adults are only 12 percent of total annual health care spending. Furthermore, children, including those with special health care needs, make up more than 50 percent of all Medicaid recipients, but account for less than 25 percent of Medicaid costs.

Children's programs are cost-effective and improve our nation's health and economy
Children's programs are a cost-effective investment in our nation's future. For example, every 1 dollar spent on the childhood vaccine series saves the healthcare system $16.50 in future medical costs. Every 1 dollar spent on high-quality home visiting programs saves up to $5.70 as a result of improved prenatal health, decreased mental health and criminal justice costs, and fewer children suffering from abuse and neglect. Every 1 dollar spent on preventative services for a pregnant woman in the WIC program saves Medicaid up to $4.20 by reducing the risk of pre-term birth and its associated costs.

Healthier children, healthier future
On behalf of the 75 million American children and their families that we serve and treat, the nation's pediatricians hope that Congress will respond to mounting evidence that child health has life-long impacts and prioritize children while determining FY 2017 Federal spending levels. Federal support for children's health programs, such as early brain and child development, parenting and health education, and preventive health services, will yield high returns for the American economy. Investing in children is not only the right thing to do for the long-term physical, mental, and emotional health of the population, but is imperative for the nation's long-term fiscal health as well.

We fully recognize the nation's fiscal challenges and respect that difficult budgetary decisions must be made; however, we do not support funding decisions made at the expense of the health and welfare of children and families. Rather, focusing on the long-term needs of children and adolescents will ensure that the United States can compete in the modern, highly-educated global marketplace. Strong and sustained financial investments in children's health care, research, and prevention programs will help keep our children healthy and pay extraordinary dividends for years to come.

There are many ways Congress can help meet children's needs and protect their health and well-being. Adequate funding for children's health programs is one of them. The American Academy of Pediatrics looks forward to working with Members of Congress to prioritize the health of our nation's children in FY 2017 and beyond. If we may be of further assistance please contact the AAP Department of Federal Affairs at 202-347-8600 or pjohnson@aap.org. Thank you for your consideration.

Written Testimony of Jill Rethman, RDH, BA
President, American Dental Hygienists' Association
On FY 2017 Appropriations for the Department of Health and Human Services Impacting Oral Health
Submitted to the
Appropriations Subcommittee on Labor, Health and Human Services, Education and Related Agencies
United States House of Representatives
The Honorable Hal Rogers, Appropriations Committee Chair
The Honorable Nita Lowey, Appropriations Committee Vice Chairwoman
The Honorable Tom Cole, Subcommittee Chair
The Honorable Rosa DeLauro, Subcommittee Ranking Member

ADHA Contacts:
Ann Battrell, MSDH, ADHA Chief Executive Officer
Ann Lynch, ADHA Governmental Affairs Director
American Dental Hygienists' Association
444 North Michigan Ave., Suite 3400, Chicago, IL 60611
312.440.8900 or annb@adha.net or annl@adha.net

Karen Sealander, ADHA Washington Counsel
McDermott Will & Emery
500 N. Capitol Street, N.W., Washington, DC 20005
202.756.8024 or ksealander@mwe.com

Introduction

The American Dental Hygienists' Association (ADHA) appreciates this opportunity to provide testimony of FY 2017 appropriations. Oral health is a part of total health and authorized oral health care programs require appropriations support in order to increase the accessibility of oral health services, particularly for the underserved. While virtually all dental disease is fully preventable, nearly 25,000,000 children eligible for dental Medicaid benefits (60%) did not receive any preventive dental services in FY 2014.[1] With the nation confronting an oral health access crisis, there is no dispute that new types of dental providers are needed; the disagreement relates to what ***types*** of new providers are needed. This underscores the need for demonstration projects under Section 340G-1 of the Public Health Service Act in order to explore what types of new providers work best in various settings. Regrettably, there is a persistent appropriations statutory provision blocking funding specifically for this grants program at the Health Resources and Services Administration (HRSA). There is simply no legal or health policy justification to perpetuate this funding block. Indeed, it is only organized dentistry that actively works to block funding for Section 340G-1. **ADHA, along with the Kentucky Dental Hygienists' Association and state dental hygiene associations across the nation, urges that the block on funding for Section 340G-1 be lifted, that $2,000,000 be appropriated for Section 340G-1 and that the following report language be included in the FY 2017 HHS funding bill:**

[1] https://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Benefits/Early-and-Periodic-Screening-Diagnostic-and-Treatment.html

Requested Report Language: "The nation continues to confront an oral health access crisis, which will not be ameliorated without better utilization of existing dental providers and exploration of new types of licensed dental providers. The Committee urges a stakeholder meeting be convened in order to determine how best to create new entry points into the oral health care delivery system for rural and other underserved populations, better utilization of existing dental personnel, and exploration of new types of dental providers."

Lifting the block on this dental workforce grants program, officially titled the Alternative Dental Health Care Providers Demonstration Program, would send an important signal to states and to HRSA that innovation in dental workforce is a meritorious undertaking. Even lifting the block and *not* funding the program would be a positive message to states. Importantly, the authorizing language requires that the grants be conducted in compliance with state law, that they must increase access to dental health care in rural and other underserved communities, and that the Institute of Medicine provide a qualitative and quantitative evaluation of the grants. **Importantly, nothing in Section 340 G-1 would enable oral health practitioners to perform dental surgery or "irreversible procedures," unless a state specifically allowed such services.** Further, because the authorizing language requires HRSA to begin the dental workforce grant program under Section 340G-1 within two years of its 2010 enactment (i.e., by 2012) and to conclude it within seven years of enactment (2017), language directing HRSA to move forward with Section 340G-1 grants despite this timeline is needed.

Widespread Support for Dental Workforce Innovation

The American Dental Association (ADA), ADHA and numerous other groups have called for the creation of new types of dental providers. Innovative oral health practitioner models were authorized in Minnesota in 2009, followed by Maine in 2014. A February 2014 Report to the Minnesota Legislature on the early impact of the new providers found that benefits include "direct cost savings, increased dental team productivity, improved patient satisfaction and lower appointment fail rates."[2] Several states have mid-level oral health practitioner legislation pending including Connecticut, Georgia, Hawaii, Kansas, Massachusetts, New Mexico, North Dakota, South Carolina, Texas, Vermont and Washington State.

Both the W.K. Kellogg Foundation and the PEW Charitable Trust Dental Campaign are investing in state efforts to increase oral health care access by adding new types of dental providers to the dental team. Groups as disparate as Families USA, Americans for Tax Reform, and Americans for Prosperity have called for exploration of new dental providers. In a January 2015 report, Families USA called for "improving access to care through greater use of mid-level providers such as nurse practitioners and dental therapists".[3] Grover Norquist, President of Americans for Tax Reform, observed in March 2015 that "It is undeniable that there is a dentist shortage". Norquist further noted that "Innovative ideas like this [mid-level dental provider] faced intense opposition but are very similar to the fights that took place decades ago with the

[2] http://www.health.state.mn.us/divs/orhpc/workforce/dt/dtlegisrpt.pdf
[3] http://familiesusa.org/press-release/2015/families-usa-proposes-health-reform-20

emergence of nurse practitioners." Americans for Prosperity wrote in January 2015 that states should be "free to innovate" in the dental workforce to solve access issues.

The National Dental Association, representing 6,000 Black dentists, released its "Position on Access to Care and Emerging Workforce Models" in July 2014, which stated that the NDA "supports the development and continuation of demonstration projects that can demonstrate the impact and effectiveness of Emerging Workforce Models [expanded function dental hygienists, expanded function dental assistants, or dental therapists] on access to care, and total health outcomes."[4]

The U.S. Federal Trade Commission (FTC) supported dental workforce expansion in November 2014, noting that expanding the supply of dental therapists is "likely to increase the output of basic dental services, enhance competition, reduce costs and expand access to dental care."[5] In January, 2016, the FTC noted that "By eliminating the direct supervision requirement for dental hygienists' services delivered in expanded safety-net setting...H.B. 684 will likely promote greater competition in the provision of preventive dental care services, leading to increased access and more cost-effective care...."[6] Importantly, the FTC observed that "authoritative sources have found no countervailing health or safety benefits to health care consumers from such [direct supervision] requirements."[7]

The National Governors Association's January 2014 issue brief on "The Role of Dental Hygienists in Providing Access to Oral Health Care" found that "innovative state programs are showing that increased use of dental hygienists can promote access to oral health care, particularly for underserved populations, including children" and that "such access can reduce the incidence of serious tooth decay and other dental disease in vulnerable populations."[8]

The Department of Health and Human Services, in its Oral Health Strategic Framework, called for expanding the number of health-care settings that provide oral health care and urged strengthening the oral health workforce and expanding the capabilities of existing providers.[9]

Dentist Shortage and Dental Hygienist Surplus Demand Better Utilization of Dental Hygienists

In February 2015, HRSA projected that all 50 states and the District of Columbia will experience a shortage of dentists by 2025. In contrast, there will be an excess supply of dental hygienists

---

[4] (http://ndaonline.org/position-on-access-to-care-and-emerging-workforce-models)

[5] https://www.ftc.gov/system/files/documents/advocacy_documents/ftc-staff-comment-commission-dental-accreditation-concerning-proposed-accreditation-standards-dental/141201codacomment.pdf

[6] https://www.ftc.gov/system/files/documents/advocacy_documents/ftc-staff-comment-georgia-state-senator-valencia-seay-concerning-georgia-house-bill-684/160201gadentaladvocacy.pdf?utm_source=govdelivery

[7] *Ibid.*

[8] http://www.nga.org/files/live/sites/NGA/files/pdf/2014/1401DentalHealthCare.pdf

[9] HHS Oral Health Strategic Framework, 2014-2017, Public Health Reports, Vol. 131, March-April 2016, pp248-249. http://www.publichealthreports.org/issueopen.cfm?articleID=3498

at the national level while five states (MI, MT, ND, SD, and WV) will experience dental hygienist shortages from 21-93 FTEs.[10]

Title VII Program Grants to Expand and Educate the Dental Workforce –
ADHA Urges Funding at a level of $35.8 million in FY 2017
A number of existing grant programs offered under Title VII support health professions education programs, students, and faculty. ADHA is pleased dental hygienists are recognized as primary care providers of oral health services and are included as eligible to apply for several grants offered under the "General, Pediatric, and Public Health Dentistry" grants. With millions more Americans eligible for dental coverage in coming years, it is critical that the oral health workforce is bolstered. Dental and dental hygiene education programs currently struggle with significant shortages in faculty and there is a dearth of providers pursuing careers in public health dentistry and pediatric dentistry. Securing appropriations to expand the Title VII grant offerings to additional dental hygienists and dentists will provide much needed support to programs, faculty, and students in the future.

Oral Health Programming within the Centers for Disease Control –
Fund at a level of $19 million in FY 2017
ADHA joins with others in the dental community in urging $19 million for oral health programming within the Centers for Disease Control. This funding level will enable CDC to continue its vital work to control and prevent oral disease, including vital work in community water fluoridation. Federal grants will serve to facilitate improved oral health leadership at the state level; support the collection and synthesis of data regarding oral health coverage and access, promote the integrated delivery of oral health and other medical services; enable states to be innovative and promote a data-driven approach to oral health programming.

National Institute of Dental and Craniofacial Research –
Fund at a level of $452 million in FY 2017
The National Institute of Dental and Craniofacial Research (NIDCR) cultivates oral health research that has led to a greater understanding of oral diseases and their treatments and the link between oral health and overall health. Research breeds innovation and efficiency, both of which are vital to improving access to oral health care services and improved oral status of Americans in the future. ADHA joins with others in the oral health community to support NIDCR funding at a level of $452 million in FY 2016.

Conclusion
ADHA is the largest national organization representing the professional interests of more than 185,000 licensed dental hygienists across the country. Thirty-nine states enable patients to directly access oral health services provided by dental hygienists in settings outside the private dental office. Seventeen State Medicaid programs (AZ, CA, CO, CT, ME, MA, MI, MN, MO, MT,

[10] HRSA March 2015 "National and State-Level Projections of Dentists and Dental Hygienists in the U.S., 2012-2025" http://bhpr.hrsa.gov/healthworkforce/supplydemand/dentistry/nationalstatelevelprojectionsdentists.pdf

NE, NM, NV, OR, RI, WA and WI) provide direct reimbursement to dental hygienists for oral health services provided to Medicaid-eligible individuals.

ADHA urges the Subcommittee to lift the block on funding for Section 340G-1 of the PHSA, dental workforce demonstration grants, in its FY 2017 HHS funding bill. It is time for an evidence-based decision to be made on this grant program for the underserved. Lifting the block on funding for these dental workforce grants would be an important signal to states and to health care stakeholders that exploring new ways of bringing oral health services to the underserved is a meritorious expenditure of resources. Without the appropriate supply, diversity and distribution of the oral health workforce, the current oral health access crisis will only be exacerbated.

In closing, ADHA recommends funding at a level of $2 million for FY 2017 to support these vital dental workforce demonstration projects. ADHA also requests that report language (see page 2) be included noting that the Committee recognizes that the oral health access crisis will not be ameliorated without better utilization of existing dental providers and exploration of new types of licensed dental providers. In addition, ADHA urges that this Subcommittee convene a stakeholder meeting in order to move beyond the tired appropriations rider that blocks funding for Section 340G-1, a dental workforce demonstration program to improve access to care for vulnerable and underserved populations. Thank you for the opportunity to submit the views of the ADHA.

DM_US 71822788-1.014468.0010

Easter Seals

Office of Public Affairs
1425 K Street, N.W.
Suite 200
Washington, DC 20005
202.347.3066 phone
202.347.7385 tty
202.737.7914 fax
www.easterseals.com

Testimony of Easter Seals, Inc.
Prepared for the
Subcommittee on Labor, Health and Human Services, and Education, and Related Agencies
Addressing the
Department of Labor Veterans Employment & Training Account
Department of Labor Employment and Training Administration, and
Department of Education Special Education Account

Easter Seals respectfully asks that you add four key federal programs to your fiscal year (FY) Labor-HHS-Education appropriations Member submission form to help homeless veteran and older adult find jobs in their communities and to ensure that children with disabilities can access the early intervention and educational supports they require to grow and develop.

Easter Seals is a national nonprofit that break down barriers for Americans through individualized, evidence-based services from one of our 74 statewide and local affiliates. We urge you to prioritize funding, at no less than the President's FY 2017 budget recommendations, for the Homeless Veterans' Reintegration Program ($50,000,000), Early Intervention Grants for Infants and Families ($503,556,000), Community Service Employment for Older Americans ($434,371,000), and Preschool Grants for Children with Disabilities ($403,238,000).

HOMELESS VETERANS' REINTEGRATION PROGRAM
Easter Seals Request: $50,000,000

The Homeless Veterans' Reintegration Program (HVRP) provides job training, counseling, and placement services to help homeless veterans reintegrate into society and the labor force. With the dramatic decrease in veterans' homelessness since 2010, HVRP employment services are needed now more than ever to ensure those veterans who were formerly homeless secure employment to help them maintain their housing. Recognizing the growing demand for services among homeless and at-risk veterans, Congress has authorized HVRP funding at $50 million annually. The President's FY 2017 budget request would, for the first-time, meet this authorized level and allow community providers to serve an additional 5,000 veterans.

Submission Form Information:

Program:	Homeless Veterans' Reintegration Program
Federal Department or Agency:	U.S. Department of Labor
Account:	Veterans Employment & Training
FY 2017 LHHS Request:	$434,371,000

FY 2017 President's Budget:	$434,371,000
FY 2016 Enacted:	$434,371,000
FY 2015 Enacted:	$434,371,000
FY 2014: Enacted:	$434,371,000

EARLY INTERVENTION GRANTS FOR INFANTS AND FAMILIES
Easter Seals FY 2017 Request: $503,556,000

The Early Intervention Grants for Infants and Families program (also known as Part C of the Individuals with Disabilities Education Act) provides formula grants to all 50 states to implement statewide systems of coordinated, comprehensive, multidisciplinary, interagency programs and make early intervention services available to children with disabilities, aged birth through 2. The increased prevalence of childhood disability and stagnant funding levels has meant fewer children benefit from the early intervention services and supports they need to meet key developmental milestones. The President's recommended increase will help to demonstrate innovative strategies to meet the needs of at-risk infants and toddlers and increase the state grant size.

Submission Form Information:

Program:	Early Intervention Grants for Infants and Families
Federal Department or Agency:	U.S. Department of Education
Account:	Special Education
FY 2017 LHHS Request:	$503,556,000
FY 2017 President's Budget:	$503,556,000
FY 2016 Enacted:	$458,556,000
FY 2015 Enacted:	$438,556,000
FY 2014: Enacted:	$438,498,000

COMMUNITY SERVICE EMPLOYMENT FOR OLDER AMERICANS
Easter Seals FY 2017 Request: $442,263,738

The Community Service Employment for Older Americans program (also known as the Senior Community Service Employment Program or SCSEP) assists unemployed, low-income older adults in developing new work skills and experience through paid, work-based training in their communities. SCSEP-funded services are available in nearly all 3,000 U.S. counties and territories. In addition to helping thousands of older Americans find jobs, the program strengthens communities through the training contributions participants make to local nonprofit and public facilities, such as libraries, schools and senior centers. Easter Seals was disappointed that the President's request failed to account for the increased operating costs (nearly $8 million) due to increases in state minimum wages. Easter Seals requests no less than the President's FY 2017 budget request for SCSEP.

Submission Form Information:

Program:	Community Service Employment for Older Americans
Federal Department or Agency:	U.S. Department of Labor
Account:	Employment & Training Administration
FY 2017 LHHS Request:	$434,371,000

FY 2017 President's Budget:	$434,371,000
FY 2016 Enacted:	$434,371,000
FY 2015 Enacted:	$434,371,000
FY 2014: Enacted:	$434,371,000

PRESCHOOL GRANTS FOR CHILDREN WITH DISABILITIES
Easter Seals FY 2017 Request: $403,238,000

Preschool Grants for Children with Disabilities (Part B of the Individuals with Disabilities Education Act) supports the educational needs of children between the ages of 3 and 5 years who have disabilities and also require special education services. Through IDEA, Congress guaranteed the right of these children to free, appropriate, public education and set a goal of providing $1500 to states for each eligible child. Past funding levels have fallen well short of this per pupil goal. The President proposes to build upon the investments made last year by Congress by recommending $46 more per child, for an average of $535 per child. Easter Seals support no less than the President's FY 2017 proposal to ensure the only Federal program dedicated to preschool-aged children with disabilities has resources to meet its statutory obligations in providing these children with the critical academic and behavior supports.

Submission Form Information:

Program:	Preschool Grants for Children with Disabilities
Federal Department or Agency:	U.S. Department of Education
Account:	Special Education
FY 2017 LHHS Request:	$403,238,000
FY 2017 President's Budget:	$403,238,000
FY 2016 Enacted:	$368,238,000
FY 2015 Enacted:	$353,238,000
FY 2014: Enacted:	$353,238,000

Thank you in advance for your consideration of Easter Seals' Labor-HHS-Education funding priorities for FY 2017. Please let us know if you have any questions or need any additional information in support of your submission forms. Thank you.

Written Testimony for the Record

Matthew L. Myers

President, Campaign for Tobacco-Free Kids

Subcommittee on Labor, Health and Human Services, and Education, and Related Agencies

Committee on Appropriations, United States House of Representatives

Appropriations for the Office on Smoking and Health, Centers for Disease Control and Prevention, for Fiscal Year 2017

I am Matthew Myers, President of the Campaign for Tobacco-Free Kids. I am submitting this written testimony for the record in support of funding for the Office on Smoking and Health (OSH) at the Centers for Disease Control and Prevention (CDC). We urge the Subcommittee to include at least $210 million for CDC's OSH in the Labor-HHS-Ed appropriations bill for FY 2017.

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 16 million Americans are currently living with a tobacco-caused disease.[1] Tobacco use is responsible for 32 percent of heart disease deaths, 30 percent of all cancer deaths, 87 percent of lung cancer deaths, and 61 percent of all pulmonary disease deaths.[2] Smoking shortens the life of a smoker by more than a decade and increases the risk of early death much more than other risk factors.[3]

Tobacco use almost always begins during adolescence. Ninety percent of adult smokers begin as teenagers, or earlier.[4] As youth become adults, they typically continue to use tobacco because they have become addicted to nicotine. Given the addictiveness of nicotine, smoking is not simply a matter of choice. Most adult smokers want to quit (nearly 70 percent) and wish they never started (about 90 percent).[5] But overcoming an addiction to nicotine is difficult, and tobacco users often must make multiple quit attempts before they succeed.

Fortunately, we know how to reduce tobacco use. Smoking rates have been cut by more than half since the first Surgeon General's report on the harms from smoking in 1964.[6] According to recent surveys, the smoking rate among adults declined nearly 20 percent from 2005 to 2014, and the smoking rate among 12th graders declined nearly 70 percent between 1997 and 2015.[7] This progress has been driven by the implementation of policies and programs that have proven to be highly effective in preventing youth from starting to use tobacco products and helping adult tobacco users to quit.

These successful efforts to reduce tobacco use have generated enormous gains for public health. People are living longer, healthier lives. Over the past 50 years, tobacco control measures have prevented about eight million people from dying prematurely.[8] About 30 percent of the gain in life expectancy between 1964 and 2012 is due to efforts to reduce tobacco use, an especially remarkable achievement when one considers the enormous medical innovations that occurred during this time.[9]

The CDC's Office on Smoking and Health plays a critical role in continuing our nation's successful efforts to reduce the toll that tobacco takes on our health. OSH translates science into best practices for reducing tobacco use, provides funding and technical support to implement them, and monitors progress in reducing tobacco use rates.

Since 2012, OSH has funded a national media campaign, Tips from Former Smokers (Tips), to encourage smokers to quit. It features real people discussing the harsh reality of living with a disease caused by smoking, and it has proven to be highly successful and cost-effective. A recent evaluation found that over a nine-week period in 2014 the Tips media campaign motivated 1.8 million smokers to make a quit attempt and helped 104,000 people to quit.[10] CDC estimates that over the past three years this media campaign has motivated about 5 million smokers to make a quit attempt, helped 300,000 smokers to quit for good, and saved at least 50,000 people from premature death.[11] It cost just $393 for each year of life saved, which is considered a "best buy" in public health.[12]

CDC also provides funding to states for quitlines, which provide telephone-based counseling services to help tobacco users to quit and, in some states, provide tobacco cessation medications. Smokers who use quitlines are at least two to three times more likely to succeed than those who try to quit on their own.[13]

In addition, CDC provides grants to all 50 states and the territories to help establish and maintain tobacco prevention and cessation programs at the state and local level. Comprehensive state tobacco programs like the ones CDC helps to maintain have been found to be cost effective. A study of Washington state's tobacco prevention and cessation program found that for every dollar spent by the state on tobacco prevention, the state saved more than $5 in reduced hospitalization costs.[14]

CDC also conducts important surveillance and other research on tobacco use and its impact on health. For example, the National Youth Tobacco Survey, which CDC conducts with FDA, found that e-cigarette use among youth tripled between 2013 and 2014.[15]

Last year, the House Labor-HHS-Ed appropriations bill for FY 2016 would have reduced funding for OSH by 50 percent, from $216.5 million to $105.5 million. This substantial reduction would have undermined CDC's efforts to prevent youth from starting to use tobacco and to help

adults to quit. Programs we know are working would have been curtailed and possibly eliminated. CDC would have had to end its successful and cost-effective media campaign. It would also likely have had to reduce funding for state quitlines and state and local tobacco prevention and cessation programs.

We were pleased that the Senate Labor-HHS-Ed appropriations bill for FY 2016 would have provided level funding for OSH and were relieved that the Consolidated Appropriations Act for FY 2016 included a much smaller cut than what the House had proposed.

We urge the Subcommittee to provide at least $210 million for OSH for FY 2017, which is the funding level enacted for FY 2016. Without continued attention and resources, we risk undermining the progress that has been made in reducing the disease and death caused by tobacco use. We risk more cancers, heart disease, respiratory disease, and other tobacco-caused diseases and more people dying years earlier than if they did not smoke. Without urgent action, 5.6 million children alive today will die prematurely from a smoking-related disease.[16]

The federal government cannot afford to take a hands-off approach to tobacco use. Tobacco use not only harms the health of tobacco users but also burdens families, the health care system, and government budgets. It is responsible for approximately $170 billion in health care costs each year. Nearly 60 percent of these health care costs are paid by government programs such as Medicare and Medicaid.[17]

At a time when Congress is working on a bipartisan basis to facilitate the development of new cures and treatments for devastating diseases, the Subcommittee should, at a minimum, maintain existing funding for programs that have proven effective at preventing cancers, heart disease, chronic obstructive pulmonary disease (COPD) and other diseases caused by tobacco. At a time of concern about high health care costs, the Subcommittee should, at a minimum, maintain existing investments to address risk factors like tobacco use that, if left unaddressed, will lead to higher medical costs for treating preventable diseases in the future.

We appreciate the opportunity to share our views on the importance of OSH's work and the need to maintain, at a minimum, its current funding level.

---

[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/.

[2] HHS, *The Health Consequences of Smoking – 50 Years of Progress: A Report of the Surgeon General*, 2014

[3] HHS, *The Health Consequences of Smoking – 50 Years of Progress: A Report of the Surgeon General*, 2014

[4] Substance Abuse and Mental Health Services Administration (SAMHSA), Calculated based on data in 2013 *National Survey on Drug Use and Health*

[5] HHS, *The Health Consequences of Smoking – 50 Years of Progress: A Report of the Surgeon General*, 2014; and Fong, G., et al., "The Near-Universal Experience of Regret Among Smokers in Four Countries: Findings from the International Tobacco Control Policy Evaluation Survey," *Nicotine & Tobacco Research*, Vol. 6, Supplement 3, December 2004.

[6] HHS, *The Health Consequences of Smoking – 50 Years of Progress: A Report of the Surgeon General*, 2014

[7] Ahmed, J., et al., "Current Cigarette Smoking Among Adults – United States, 2005-2014;" *Morbidity and Mortality Weekly Report*, November 13, 2015: 64(44) http://www.cdc.gov/mmwr/preview/mmwrhtml/mm6444a2.htm?s_cid=mm6444a2_w; and Monitoring the Future, University of Michigan, December 2015

[8] Holford, T., et al., "Tobacco Control and the Reduction in Smoking-Related Premature Deaths in the United States, 1964-2012," *Journal of the American Medical Association*, January 8, 2014: 311(2)

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

[10] Neff, L., et al, "Evaluation of the National Tips From Former Smokers Campaign:the 2014 Longitudinal Cohort," *Prev Chronic Dis* 2016; 13: 1S0556

[11] Centers for Disease Control and Prevention (CDC), FY 2017 Justification of Estimates for Appropriations Committees http://www.cdc.gov/budget/documents/fy2017/fy-2017-cdc-congressional-justification.pdf

[12] Xu, Xin, et al., "Cost-Effectiveness Analysis of the First Federally Funded Antismoking Campaign," *American Journal of Preventive Medicine*, 2014

[13] Fiore, MC, et al., Treating Tobacco Use and Dependence: 2008 Update – Clinical Practice Guideline, U.S. Public Health Service, May 2008, http://www.surgeongeneral.gov/tobacco/treating_tobacco_use08.pdf

[14] Dilley, Julia A., et al., "Program, Policy and Price Interventions for Tobacco Control: Quantifying the Return on Investment of a State Tobacco Control Program," *American Journal of Public Health*, Published online ahead of print December 15, 2011. See also, Washington State Department of Health, Tobacco Prevention and Control Program, Progress Report, March 2011, http://www.doh.wa.gov/tobacco/program/reports/2011ProgReport.pdf. Washington State Department of Health, Tobacco Prevention and Control Program, News Release, "Thousands of lives saved due to tobacco prevention and control program," November 17, 2010, http://www.doh.wa.gov/Publicat/2010_news/10-183.htm.

[15] U.S. Centers for Disease Control and Prevention (CDC), "Tobacco Use Among Middle and High School Students — United States, 2011-2014," *Morbidity and Mortality Weekly Report (MMWR)* 64(14):381-385, April 2015, http://www.cdc.gov/mmwr/preview/mmwrhtml/mm6414a3.htm?s_cid=mm6414a3_e.

[16] HHS, *The Health Consequences of Smoking – 50 Years of Progress: A Report of the Surgeon General*, 2014

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

Written Statement of Richard Hamburg
Interim President and CEO, Trust for America's Health
House Appropriations Subcommittee on Labor, Health & Human Services, Education and Related Agencies

Trust for America's Health (TFAH), a nonprofit, nonpartisan organization dedicated to saving lives by working to make disease prevention a national priority, is pleased to provide written testimony on TFAH's funding priorities. As this subcommittee works to develop a FY17 Labor, Health & Human Services, Education and Related Agencies (LHHS) appropriations bill, I urge you to ensure adequate funding for public health, prevention and preparedness programs at the Centers for Disease Control and Prevention (CDC) and other public health agencies.

Every American should have the opportunity to be as healthy as he or she can be, but today this is not the case. The effects of sequestration and years of funding cuts as a result of discretionary budget caps under the Budget Control Act and related law have fundamentally eroded our ability to respond to disasters, prevent chronic diseases, reduce health disparities, and ensure the health of all Americans. Preventable chronic diseases such as cancer, diabetes, lung disease, heart disease and stroke are responsible for seven out of 10 deaths and cost $1.3 trillion in health care and lost productivity costs every year. While funding for some community prevention remains, notably the Racial and Ethnic Approaches to Community Health (REACH) program, we were disappointed that Congress has indicated that the Partnerships to Improve Community Health (PICH) program will not be funded following FY16.

In 2015 and early 2016, the nation experienced the first domestic cases of Zika virus, and increasingly severe cold and drought, wildfires, tornados, and mudslides. These events illustrated persistent gaps in the country's preparedness for diseases, disasters, and bioterrorism. Each of these required a public health and healthcare response, but federal, state, and local budget cuts have threatened more than a decade of progress.

Finally, prescription drug abuse has quickly grown into a full-blown epidemic, with more than 6.1 million Americans abusing or misusing prescription drugs. Prescription drug related deaths now outnumber those from heroin and cocaine combined and drug overdose deaths exceed motor vehicle-related deaths in a majority of states. Addressing this epidemic requires investments in prevention and treatment of those suffering from substance abuse addiction. Building a public health system prepared to meet the challenges of protecting Americans from natural and man-made threats and preventing disease can only occur with a strong and steady baseline of funding. Below are TFAH's recommendations for meeting that challenge.

The Prevention and Public Health Fund (PPHF)

TFAH was pleased to see Congress continue to exercise its authority to allocate the Prevention and Public Health Fund in FY14-16, and we urge the Committee to do so again in the FY17 appropriations bill. To date, PPHF has invested more than $6 billion to support state and local efforts to transform communities, build epidemiology and laboratory capacity, address healthcare associated infections, train the nation's public health and health

workforce, screen for and prevent cancer, expand access to vaccines, reduce tobacco use, and help control the obesity epidemic.

Centers for Disease Control and Prevention (CDC)

From FY10-13, the CDC saw its budget authority cut by 18 percent. The FY16 Omnibus Appropriations measure provided CDC with an increase of just over $277 million, including $892.3 million from the Prevention and Public Health Fund, but included a $22 million decrease for chronic disease programs. The President's FY17 budget cuts that number by nearly an additional $60 million. Scarce resources means CDC will be forced to make extremely difficult choices. **We urge the Committee to oppose the overall $164 million program level decrease included in the President's budget for FY 2017 and appropriate $7.8 billion for CDC programs.**

National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP) – CDC

We must continue to engage not only health systems but other sectors of society, such as education, housing, business, planning, and faith-based institutions, to help communities to make the healthy choice the easy choice for everyone. CDC's Chronic Disease Center has made progress in moving away from the traditional categorical approach to funding disease prevention and toward more coordinated, cross-cutting strategies. **We encourage the Committee to fund the Chronic Disease Center's Division of Nutrition, Physical Activity, and Obesity at $61 million.** This increase of $11.08 million would permit CDC to increase enhanced support to state health departments in the remaining 18 states and the District of Columbia. **TFAH also recommends that the Racial and Ethnic Approaches to Community Health (REACH) program be funded at $51 million to fund new three-year cooperative agreements to eligible grantees.** This investment would ensure the continued success of this community-based program aimed at reducing health disparities amongst minority populations.

National Center for Environmental Health (NCEH) – CDC

Critical programs conducted at the CDC National Center for Environmental Health support our chronic disease prevention and public health preparedness efforts. Yet it remains one of the most critically underfunded parts of CDC. The Center's Health Tracking Program funds 25 states and one city to collect and share data for cancer, reproductive health outcomes, birth defects and demographics and socioeconomic status, outdoor air quality, drinking water quality, hospitalizations for asthma, cardiovascular disease, carbon monoxide poisoning, childhood lead poisoning, community design, and developmental disabilities. The Flint, Michigan water crisis underscores the need for a stronger environmental health surveillance program. **We recommend that you fund the Health Tracking Program at $50 million in FY17.** This amount would represent a down payment towards fully funding the Network within the next three years.

Public Health Emergency Preparedness (PHEP) Cooperative Agreements – CDC

The Public Health Emergency Preparedness (PHEP) program, administered by CDC, is the only federal program that supports the work of state and local health departments to prepare for all types of disasters, including bioterror attacks, natural disasters, and infectious disease outbreaks The grants fund all 50 states, as well as territories and cities, to develop core capabilities like laboratory testing, surveillance and epidemiology, and incident management. **TFAH recommends that the Public Health Emergency Preparedness Cooperative Agreements continue to be funded at $675 million in FY17** to help states and localities address vulnerabilities in their preparedness capabilities.

Hospital Preparedness Program – ASPR

The Hospital Preparedness Program (HPP), administered by the Assistant Secretary for Preparedness and Response (ASPR), provides funding and technical assistance to prepare the health system to respond to and recover from a disaster. The grants support nearly 500 healthcare coalitions with 24,000 participating facilities from across the health system, an increase of 47 percent in membership since 2013. ASPR supports coalitions to develop key capabilities, including health system preparedness and recovery, emergency operations coordination, information sharing, medical surge and responder safety. Most jurisdictions receive no other federal or state support for health system preparedness. **TFAH recommends $300 million for FY17 for HPP,** as it marks the beginning of the new project period which will shift the focus of the program from supporting establishment of healthcare coalitions to ensuring they are ready to respond to emergencies.

Global Health Protection

The CDC's Division of Global Health Protection (DGHP) protects Americans and people around the world from the leading public health threats. The Division builds the capacities of local, national and regional public health to detect emerging threats, prevent disease and prepare for and respond to public health emergencies. The centerpiece of the division is the Global Disease Detection (GDD) program, which supports GDD Centers in 10 countries (Bangladesh, China, Egypt, Georgia and the South Caucasus, Guatemala and Central America, India, Kazakhstan and Central Asia, Kenya, South Africa and Thailand) to conduct outbreak response, pathogen discovery, training and surveillance. The regional center in Guatemala has been assisting with the Zika response, including surveillance and outbreak investigation support. **TFAH recommends $65.2 million for the Division of Global Health Protection, including a $5 million increase for Global Disease Detection** to establish a new GDD center.

Combating Opioid Abuse – CDC & SAMHSA

Over the past several years, the overuse and misuse of opioids, both prescribed and illicit, has become a public health epidemic. Deaths from prescription painkillers have quadrupled since 1999, killing more than 28,000 people in the U.S. in 2014. **TFAH supports the President's budget request for $80 million for the CDC Injury Center's Injury Prevention Activities line.** The $10 million increase in FY17 will allow the CDC to disseminate opioid prescribing

guidelines for chronic pain, which are currently under development. These guidelines will be an important tool for prescribers to make informed decisions about when opioid treatment is necessary, with the understanding that some patients suffering from chronic pain do need access to these medications. This will also allow the Injury Center to continue their work supporting support drug overdose prevention programs in all 50 states.

TFAH also recommends $20 million for the Substance Abuse and Mental Health Services Administration (SAMHSA) to continue the Grants to Prevent Prescription Drug/Opioid Overdose Related Deaths (PDO) program, an increase of $8 million, which will would allow SAMHSA to expand the reach of this program to at least eight additional states which are heavily impacted by opioid abuse and help equip and train state and local health departments, drug treatment and recovery programs, community-based overdose prevention programs and first responders with devices that rapidly reverse the effects of opioids.

TFAH supports $50 million (a $25 million increase) for SAMHSA to expand access to medication assisted treatment, which is currently unavailable for many Americans who desperately need it. Additionally, **TFAH recommends a $50 million increase for the Substance Abuse Prevention and Treatment Block Grant (SAPTBG) to help expand access to substance abuse treatment**. While there has been more than a five-fold increase in treatment admissions in the past decade, millions more are going untreated. While SAPTBG received a much needed increase in FY16, it had been flat funded for the past several years and has not kept up with inflation.

Conclusion

Approximately seventy-five percent of the CDC's annual budget flows to states, communities, tribes, and territories in the form of grants and contracts to state and local public health departments, and community partners to give them the tools they need to conduct critical public health and prevention activities, such as protecting us from infectious diseases by combating healthcare-associated infections by delivering immunizations, ensuring adequate public health emergency preparedness, and conducting nonstop disease surveillance. Investing in disease prevention is the most effective, common-sense way to improve health and address our long-term deficit. Thank you for your consideration.

Kim Bischoff, Executive Director

The Neurofibromatosis (NF) Network

Thank you for the opportunity to submit testimony to the Subcommittee on the importance of continued funding at the National Institutes of Health (NIH) for research on Neurofibromatosis (NF), a genetic disorder closely linked to many common diseases widespread among the American population. My name is Kim Bischoff and I am the Executive Director of the Neurofibromatosis (NF) Network, a national organization of NF advocacy groups. We respectfully request that you include the following report language on NF research at the National Institutes of Health within your Fiscal Year 2017 Labor, Health and Human Services, Education Appropriations bill.

Neurofibromatosis [NF] *– The Committee supports efforts to increase funding and resources for NF research and treatment at multiple NIH Institutes, including NCI, NINDS, NIDCD, NHLBI, NICHD, NIMH, NCATS, and NEI. Children and adults with NF are at significant risk for the development of many forms of cancer; the Committee encourages NCI to increase its NF research portfolio in fundamental basic science, translational research and clinical trials focused on NF. The Committee also encourages the NCI to support NF centers, NF clinical trials consortia, NF preclinical mouse models consortia and NF-associated tumor sequencing efforts. Because NF causes brain and nerve tumors and is associated with cognitive and behavioral problems, the Committee urges NINDS to continue to aggressively fund fundamental basic science research on NF relevant to nerve damage and repair. Based on emerging findings from numerous researchers worldwide demonstrating that children with NF are at significant risk for autism, learning disabilities, motor delays, and attention deficits, the Committee*

encourages NINDS, NIMH and NICHD to expand their investments in laboratory-based and clinical investigations in these areas. Since NF2 accounts for approximately 5 percent of genetic forms of deafness, the Committee encourages NIDCD to expand its investment in NF2 basic and clinical research. NF1 can cause vision loss due to optic gliomas, the Committee encourages NEI to expand its investment in NF1 basic and clinical research.

On behalf of the Neurofibromatosis (NF) Network, I speak on behalf of the 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 a clinical trial of the statin drug Lovastatin, as well as other categories of drugs.

Bone Repair

At least a quarter of children with NF1 have abnormal bone growth in any part of the skeleton. In the legs, the long bones are weak, prone to fracture and unable to heal properly; this can require amputation at a young age. Adults with NF1 also have low bone mineral density, placing them at risk of skeletal weakness and injury. Research currently being done to understand bone biology and repair will pave the way for new strategies to enhancing bone health and facilitating repair.

Pain Management

Severe pain is a central feature of Schwannomatosis, and significantly impacts quality of life. Understanding what causes pain, and how it could be treated, has been a fast-moving area of NF

research over the past few years. Pain management is a challenging area of research and new approaches are highly sought after.

Nerve Regeneration

NF often requires surgical removal of nerve tumors, which can lead to nerve paralysis and loss of function. Understanding the changes that occur in a nerve after surgery, and how it might be regenerated and functionally restored, will have significant quality of life value for affected individuals. Light-based therapy is being tested to dissect nerves in surgery of tumor removal. If successful it could have applications for treating nerve damage and scarring after injury, thereby aiding repair and functional restoration.

Wound Healing, Inflammation and Blood Vessel Growth

Wound healing requires new blood vessel growth and tissue inflammation. Mast cells, important players in NF1 tumor growth, are critical mediators of inflammation, and they must be quelled and regulated in order to facilitate healing. Researchers have gained deep knowledge on how mast cells promote tumor growth, and this research has led to ongoing clinical trials to block this signaling, resulting in slower tumor growth. As researchers learn more about blocking mast cell signals in NF, this research can be translated to the management of mast cells in wound healing.

Cancer

NF can cause a variety of tumors to grow, which includes tumors in the brain, spinal cord and nerves. NF affects the RAS pathway which is implicated in 70% of all human cancers. Some of these tumor types are benign and some are malignant, hard to treat and often fatal. Previous studies have found a high incidence of intracranial glioblastomas and malignant peripheral nerve sheath tumors (MPNSTs), as well as a six fold incidents of breast cancer compared to the general

population. One of these tumor types, malignant peripheral nerve sheath tumor (MPNST), is a very aggressive, hard to treat and often fatal cancer. MPNSTs are fast growing, and because the cells change as the tumor grows, they often become resistant to individual drugs. Clinical trials are underway to identify a drug treatment that can be widely used in MPNSTs and other hard-to-treat tumors.

The enormous promise of NF research, and its potential to benefit over 175 million Americans who suffer from diseases and conditions linked to NF, has gained increased recognition from Congress and the NIH. This is evidenced by the fact that numerous institutes are currently supporting NF research, and NIH's total NF research portfolio has increased from $3 million in FY1990 to an estimated $22 million in FY2016. 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 NF research and will continue to work with you to ensure that opportunities for major advances in NF research are aggressively pursued. Thank you.

Outside Witness Testimony

Professor Robert Moffitt, Chair, Committee on Economic Statistics, American Economic Association

Prepared for the Subcommittee on Labor, Health and Human Services, Education, and Related Agencies, Committee on Appropriations, U.S. House of Representatives Regarding the Bureau of Labor Statistics, U.S. Department of Labor

April 7, 2016

Chairman Blunt, Ranking Member Murray, and members of the Subcommittee, I am Robert Moffitt, Professor of Economics at the Johns Hopkins University and Chair of the Committee on Economic Statistics of the American Economic Association (AEA), the primary professional association of economists in the United States. On behalf of the Committee, I am pleased to provide this testimony in support of the programs of the Bureau of Labor Statistics, U.S. Department of Labor.

The AEA has about 20,000 members. As the Bureau of Labor Statistics (BLS) indicates that the nation has 21,500 jobs for economists, it is reasonable to suggest that the AEA represents a sizable proportion of the profession.

The charter of the AEA states our organization's mission:

1. The encouragement of economic research, especially the historical and statistical study of the actual conditions of industrial life.
2. The issue of publications on economic subjects.
3. The encouragement of perfect freedom of economic discussion. The Association as such will take no partisan attitude, nor will it commit its members to any position on practical economic questions.

Succinctly put, the AEA promotes the conduct, publication, and discussion of economic research based on historical and statistical study. In 1885, the AEA's founders sought to migrate the economics profession from the realm of philosophy to that of the social sciences. Since that time, the results of AEA members' work has guided the development of the U.S. economy to become the largest and one of the most dynamic in the world.

As the AEA charter indicates, statistics are the lifeblood of economic research. The growth and achievements of our profession would not have been possible without the sustained work over two centuries of the U.S. Congress to create, direct, and fund a robust, inventive, adaptive national statistical system.

At the core of that system is the Bureau of Labor Statistics, the nation's oldest continuously operating principal federal statistical agency—created by Congress one year before the AEA's founding. In a real sense, the BLS and the economics profession have grown up together. Each has made the work of the other possible.

Since Congress established the BLS, it has regularly expanded the agency's mandated duties.[1] The topics of these responsibilities are reflected in the four BLS program accounts – labor force statistics, prices and cost of living, compensation and working conditions, and productivity and technology. Congress has made clear that it has given the BLS these responsibilities in order to promote several important public policy goals:

- Effective fiscal and monetary policy
- U.S. businesses competitive in world markets
- Efficient U.S. markets for labor, goods, and services
- Research that describes and explains the current and historical dynamics of the U.S. economy

Given the breadth of these aims, it is fair to say that the health of the U.S. economy very much depends upon the value of the statistics produced by the BLS. In my view, that value historically has been extraordinarily high.

In recent years, however, the BLS has not received resources sufficient to fulfill its mandated duties. BLS appropriations peaked in Fiscal Year 2010 at $611.4 million. Accounting for inflation, its FY2016 appropriation of $609.0 million represents a decline of 8.9 percent in real terms (using BLS price data). The current BLS staffing level is 8.3 percent below that of 2010.

As a result of six years of significant budget shortfalls, the BLS has eliminated several data programs, reduced the reliability of a number of others, and curtailed investments in research, information technology, and staff. In FY2014, BLS ended the International Labor Comparisons and Mass Layoff Statistics programs, despite the fact that the latter is congressionally mandated. It also announced plans to stop publishing Export Price Indexes, a Principal Federal Economic Indicator, but then found temporary funding from another federal agency. Last fall, faced with uncertain appropriations, BLS considered eliminating the Job Openings and Labor Turnover Survey, the National Longitudinal Survey, the American Time Use Survey, and Employment Projections (another congressionally mandated program).

The AEA Statistics Committee strongly believes that the continuation of insufficient BLS funding is likely to have severe consequences for the capacity of the agency to serve the nation's economic policymakers, research economists, and market participants. Further, the Statistics Committee believes that the BLS's inability to measure trends in two important aspects of the economy—contingent work and employer-provided training—is detrimental to economic research that informs good economic and workforce policy. Therefore, the Statistics Committee strongly urges this Subcommittee to provide sufficient support for the BLS to continue its current programs and add surveys on the important two subjects just mentioned.

---

[1] Congress added current BLS responsibilities to the U.S. Code in 1888, 1913, 1940, 1966, 1970, 1975, and 1998. Congress most recently re-affirmed broad BLS labor force statistics responsibilities with the passage of the Workforce Innovation and Opportunity Act of 2014.

As the Subcommittee considers this request, I ask that it keep in mind some version of "dynamic scoring," that is, the full fiscal and economic impacts of appropriations to the BLS. Compared to other public policy tools, statistics is remarkably inexpensive and has an extraordinarily high return on taxpayer investment.

Thank you for your consideration of the AEA Statistics Committee's request. I very much appreciate the opportunity to provide this testimony, hope the Subcommittee finds it of value, and look forward to the Subcommittee's decision with regard to the BLS.

WRITTEN TESTIMONY SUBMITTED
to the

HOUSE COMMITTEE ON APPROPRIATIONS SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES, EDUCATION AND RELATED AGENCIES

by
Susan L. Vaughn, Director of Public Policy
for the
National Association of State Head Injury Administrators

DIRECTED AT THE DEPARTMENT OF HEALTH AND HUMAN SERVICES
ADMINISTRATION FOR COMMUNITY LIVING AND
CENTERS FOR DISEASE CONTROL AND PREVENTION

April 6, 2016

Dear Chairman Cole and Ranking Member DeLauro:

On behalf of the National Association of State Head Injury Administrators (NASHIA), thank you for the opportunity to submit testimony regarding the fiscal year 2017 appropriations for programs authorized by the Traumatic Brain Injury (TBI) Act within the U.S. Department of Health and Human Services (HHS). NASHIA, a non-profit organization, is comprised of state governmental officials who administer an array of short-term and long-term rehabilitation and community services and supports for individuals with TBI and their families necessary to live and work in the community as independently as possible. My name is Susan L. Vaughn and I am the Director of Public Policy for NASHIA, having previously worked for almost 30 years for state agencies administering an array of disability and brain injury services, including serving as the co-project director for federal grants awarded to our state through the Federal TBI State Grant Program authorized by the TBI Act.

The HHS Federal TBI State Grant Program is the *only* program that assists states in addressing the complex needs of individuals with TBI and their families. Currently, only 20 states receive grants to expand and improve service delivery, yet TBI is a leading cause of death and disability in the United States. To that end NASHIA supports **increasing the State Grant Program by $1.5 million** to fund an additional four states. It is imperative that **all** states have access to resources to address this robust population.

Federal funding is necessary to offer incentives for states to direct attention to the needs of individuals with TBI. States which have not received funding for a number of years are finding it difficult to continue their previous work, even though the numbers of individuals with TBI are increasing, especially with regard to older adults; sports-related concussions and returning servicemembers with TBI.

In a 2015 survey completed by state governmental programs and state brain injury associations, survey respondents listed the following as the top three most pressing needs in their states:

- services/alternatives for individuals with behavioral issues;
- long-term services and supports; and
- post-acute rehabilitation services.

With limited state resources to address these needs, states often place people out of state or in state institutional settings. Unfortunately, many individuals, particularly those with behavioral issues, including addiction, and poor judgment will find themselves homeless or in correctional facilities. In fact, several states are now working with their juvenile justice and correctional systems to screen incidence of TBI within the incarcerated population and are finding alarming results. These states are now conducting training with corrections staff and law enforcement in order for them to understand how to address their behaviors and assist with identifying community resources upon release hoping for successful community re-entry. The federal program has played a critical role in helping states to address these issues.

We are pleased that the HHS Secretary has transferred the Federal TBI Program from the Health Resources and Services Administration to the Administration for Community Living (ACL) following the passage of the reauthorization of the TBI Act in 2014. We also recognize and appreciate the Committee's support of this transfer in the fiscal year 2016 appropriations process. NASHIA believes that the program transfer will align the program better with other disability programs offering services across the lifespan and to maximize resources accordingly, as well as benefit from research conducted by the TBI Model Systems funded by the National Institute on Disability, Independent Living and Rehabilitation Research also housed in the ACL. While our members are especially interested in federal funding that assists states in providing services, members also support funding for injury prevention to reduce the incidence of TBI and research to further the field in providing appropriate and effective treatment and service delivery.

For fiscal year 2017, NASHIA supports an a**dditional $5,000,000** for the Centers for Disease Control and Prevention's (CDC) National Center for Injury Prevention and Control to establish and oversee a national concussion surveillance system to accurately determine the incidence of concussions, particularly among the children and youth. With the requested increase of $5,000,000, CDC will launch a national surveillance system on concussions, making the agency fully responsive to the recommendations issued in a 2013 report by the National Academies of Sciences, Engineering, and Medicine (formerly known as the Institute of Medicine, or the IOM). The report specifically called on 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.

As you are probably aware, all 50 states and the District of Columbia, have enacted return to play laws to address concussion management in youth athletics. The data

gathered from the national surveillance system will help states and local educational systems by having data regarding the incidence, prevalence, and outcomes of sports-related concussions in order to carry out their policies according to their state law. Currently, data is only collected when injury occurs in a school athletic setting and through emergency room visits.

In closing, over the past thirty years, states have initiated efforts to develop capacity for offering information and referral services, service coordination, rehabilitation, in-home support, personal care, counseling, transportation, housing, vocational and other support services for persons with TBI and their families. These services, however, vary in size and scope across the country and even within a state, creating a patchwork of services.

Twenty-four States have enacted legislation to assess fines or surcharges to traffic related offenses or other criminal offenses and/or assessed additional fees to motor vehicle registration or drivers license to generate funding for TBI programs and services, generally referred to as trust fund programs. These laws vary significantly with regard to the amount of revenue generated, how the funds are used, and what the funds are used for. Twenty-three states have also implemented 27 brain injury Home and Community-Based Services (HCBS) Medicaid Waiver Programs to divert individuals from nursing and institutional care. At least twelve of these states have the advantage of administering both a trust fund for non-Medicaid eligible individuals or non-Medicaid services and Medicaid waiver programs for those individuals who are eligible and are in need of nursing level of care. Across the country, these programs are administered by state public health, Vocational Rehabilitation, mental health, Medicaid, intellectual disabilities, education or social services agencies within the states. As no two brain injuries are alike, no two states are alike with regard to how services are provided and funded.

Yet, through the TBI Act Programs, federal funding has provided an avenue for states to assess needs, develop state plans; and to implement strategies for coordinating and maximizing resources across state and local agencies and to build partners to sustain these efforts. We ask that you continue to fund and increase this important program, as well as to establish the CDC national concussion surveillance system to address this critical issue.

Should you wish additional information, please do not hesitate to contact Rebeccah Wolfkiel, Governmental Consultant, at 202-480-8901 (office) or 717-250-6796 (cell) or email: rwolfkiel@ridgepolicygroup.com. You may also contact Susan L. Vaughn, Director of Public Policy, at 573-636-6946 or publicpolicy@nashia.org or William A.B. Ditto, Chair of the Public Policy Committee, at williamabditto@aol.com. Thank you.

The Association for Research in Vision and Ophthalmology
1801 Rockville Pike, Suite 400 ■ Rockville, Maryland 20852-5622
arvo@arvo.org ■ +1.240.221.2900 (Tel) ■ +1.240.221.0370 (Fax)
www.arvo.org

Written Testimony in Support of Increased Investment
In the National Institutes of Health (NIH)
And the National Eye Institute (NEI)
Labor, Health and Human Services, Education and Related Agencies Subcommittee of the
Senate Committee on Appropriations
April 13, 2016

Executive Summary

ARVO requests FY2017 appropriated NIH and NEI funding of at least $34.5 billion and $770 million, respectively, a 7.5 percent increase reflecting 5 percent real growth above projected 2.5 percent biomedical inflation.

- ARVO thanks Congress for its bipartisan action in FY2016 to increase NIH funding by $2 billion over FY2015, which is the largest actual dollar and percent increase since FY2003.
- We request a second year of budget increases to rebuild NIH's discretionary funding base—especially as it has lost 22 percent of purchasing power since FY2003, in terms of constant dollars—and to create a trend of predictable and sustained funding.
- ARVO also thanks Congress for the $31 million National Eye Institute (NEI) increase over FY2015, especially since it reflects the first time in four years that NEI's operating budget exceeds that of the pre-sequester FY2012 level, albeit by a modest 0.8 percent. Further increases this year will continue to rebuild NEI's discretionary funding base—especially as it has lost 25 percent of purchasing power since FY2003, in terms of constant dollars—and go far to ensure predictable and sustained funding.

ARVO shares the concerns expressed by bipartisan Leaders and Members of the Appropriations Committee and the LHHS Appropriations Subcommittee regarding the President's proposal to replace $1 billion of the NIH discretionary base funding with mandatory

The Association for Research in Vision and Ophthalmology
1801 Rockville Pike, Suite 400 ■ Rockville, Maryland 20852-5622
arvo@arvo.org ■ +1.240.221.2900 (Tel) ■ +1.240.221.0370 (Fax)
www.arvo.org

funding. ARVO is especially concerned that the President proposes to not only flat-fund most of the Institutes and Centers (I/Cs), but achieve this through the use of mandatory funding. In the case of the NEI, its discretionary base would be reduced to $687 million, with the difference reflecting mandatory funding that would raise it to the flat-funded level of $708 million.

ARVO looks forward to working with the appropriators to secure an increase of 5 percent real growth above inflation in FY2017 NIH and NEI funding as the next step in ensuring the security and momentum of the nation's biomedical research enterprise. We also stand ready to work with the authorizers on potential mechanisms to provide short-term "surge" funding to take advantage of the exceptional scientific opportunities now available to address current and emerging health challenges.

NEI'S BUDGET IS NOT KEEPING PACE AS THE BURDEN OF EYE DISEASE AND VISION IMPAIRMENT GROWS

NEI's FY2016 enacted funding of $715.9 million—reduced to a $708 million operating budget due to pass-throughs—reflects the first time in four fiscal years that NEI's operating budget exceeds that of the pre-sequester FY2012 funding level of $702 million. In the four years it has taken the NEI budget to grow a modest 0.8 percent, it has experienced the compounded loss of purchasing power due to biomedical inflation rates ranging from 2 to 2.5 percent.

In June 2013, Prevent Blindness (PB) released a report entitled *Cost of Vision Problems: The Economic Burden of Vision Loss and Eye Disorders in the United States,* which concluded that direct medical costs associated with vision disorders are the fifth highest—only less than heart disease, cancers, emotional disorders, and pulmonary conditions. PB's 2014 study

The Association for Research in Vision and Ophthalmology
1801 Rockville Pike, Suite 400 ■ Rockville, Maryland 20852-5622
arvo@arvo.org ■ +1.240.221.2900 (Tel) ■ +1.240.221.0370 (Fax)
www.arvo.org

projects that the total annual cost of vision disorders, which includes government, insurance, and patient costs, will grow to $373.2 billion in 2050 when expressed in 2014 dollars.

The very health of the vision research community is also at stake. The convergence of past factors which have reduced NEI funding has affected both young and seasoned investigators and threatened the continuity of research and the retention of trained staff, while making institutions more reliant on private bridge and philanthropic funding. Tahreem Mir, MD, a postdoctoral research at Wilmer Eye Institute, summed up the situation facing young investigators:

> "I have witnessed several of my colleagues, all brilliant scientists, struggle to fund their research. Many spend more time writing grants than conducting actual science."

$770 MILLION FY2017 FUNDING ENABLES NEI TO PURSUE ITS *AUDACIOUS GOAL* OF RESTORING VISION

Among NEI's most exciting pursuits is the *Audacious Goals Initiative (AGI),* which aims to restore vision within the next decade through regeneration of the retina by replacing cells that have been damaged by disease and injury and restoring their visual connections to the brain. The *AGI* builds upon discoveries from past investment in biomedical research, such as gene sequencing, gene therapy, and stem cell therapies, and combines these with new discoveries—such as imaging technologies that enable researchers to non-invasively view in real-time biological processes occurring in the retina at a cellular level—to develop new therapies for degenerative retinal disorders.

The Association for Research in Vision and Ophthalmology
1801 Rockville Pike, Suite 400 ■ Rockville, Maryland 20852-5622
arvo@arvo.org ■ +1.240.221.2900 (Tel) ■ +1.240.221.0370 (Fax)
www.arvo.org

NEI has awarded the first set of grants associated with novel imaging technologies to help clinicians observe the function of individual neurons in human patients and follow them over time as they test new therapies. It is proceeding with a second round of awards associated with identifying new factors that control regeneration and comparing the regenerative process among model organisms, rodents, and non-human primates.

These are ambitious goals that require sustained and predictable funding increases. Our nation's investment in vision health is an investment in its overall health. NEI's breakthrough research is a cost-effective investment, since it is leading to treatments and therapies that can ultimately delay, save, and prevent health expenditures, especially those associated with the Medicare and Medicaid programs. It can also increase productivity, help individuals to maintain their independence, and generally improve the quality of life—especially since vision loss is associated with increased depression and accelerated mortality.

AMERICANS FEAR VISION LOSS, WHICH IS A

GROWING PUBLIC HEALTH PROBLEM

In September 2014, the Alliance for Eye and Vision Research (AEVR) released results of a new poll entitled *The Public's Attitudes about the Health and Economic Impact of Vision Loss and Eye Disease*. It was commissioned by Research!America and conducted by Zogby Analytics with a grant from Research to Prevent Blindness (RPB), a private vision funding foundation which conducted the first-ever poll of the public's attitudes about vision loss in 1965. The 2014 poll—the most rigorous conducted to-date of attitudes about vision and vision loss among

The Association for Research in Vision and Ophthalmology
1801 Rockville Pike, Suite 400 ■ Rockville, Maryland 20852-5622
arvo@arvo.org ■ i 1.240.221.2900 (Tel) ■ i 1.240.221.0370 (Fax)
www.arvo.org

ethnic and racial groups including non-Hispanic Whites, African Americans, Hispanics, and Asian Americans—found that:

- A significant number of Americans across all racial lines rate losing their eyesight as having the greatest impact on their daily life, affecting independence, productivity, and quality of life.
- African Americans, when asked what disease or ailment is the worst that could happen, ranked blindness first, followed by HIV/AIDS. Hispanics and Asians ranked cancer first and blindness second, while non-Hispanic Whites ranked Alzheimer's disease first, followed by blindness.
- America's minority populations are united in the view that not only is eye and vision research very important and needs to be a national priority, but many feel that the current annual federal funding is not enough and should be increased.

In summary, ARVO requests FY2017 NIH funding of at least $34.5 billion and NEI funding of $770 million—the latter to better understand the scientific bases upon which to save sight and restore vision.

ABOUT ARVO

ARVO is a community of 12,000 vision researchers from 80 countries; we are the largest, most respected vision research organization in the world. Our aim to advance research worldwide into understanding the visual system and into preventing, treating and curing its disorders.

Sac and Fox Nation

920883 S. Hwy. 99 •• Building A • Stroud, OK 74079

Principal Chief KAY RHOADS
Second Chief DON W. ABNEY
Secretary MARY F. MCCORMICK
Treasurer JARED A. KING
Committee Member ROBERT E. WILLIAMSON

WRITTEN TESTIMONY OF THE HONORABLE KAY RHOADS, PRINCIPAL CHIEF
SAC AND FOX NATION
SUBMITTED TO THE HOUSE APPROPRIATIONS
SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES, EDUCATION AND RELATED AGENCIES
ON THE FY 2017 BUDGETS FOR THE BUREAU OF INDIAN AFFAIRS AND THE INDIAN HEALTH SERVICE

April 22, 2016

Chairman Cole and esteemed members of the Committee, on behalf of the Sac and Fox Nation I thank you for the opportunity to present our requests for the FY 2017 Budgets and matters for consideration for Health and Human Services and Education. The Sac and Fox Nation is home of Jim Thorpe, one of the most versatile athletes of modern sports who earned Olympic gold medals for the1912 pentathlon and decathlon.

Each of our suggestions and requests for your budgets this year is contained in more detail below. I am so pleased to be able to provide you this testimony and hope that it helps you in your many deliberations regarding the budgets for FY2017. The Sac and Fox Nation looks forward to building a positive relationship with your committee and enhancing the future of our people and our youth.

I. NATIONAL REQUESTS – EDUCATION

1. **Increase in funding directly to education departments to leave more money for programs.** The FY2017 budget identifies funding directly for education departments and this is a priority for the Sac and Fox Nation. Having direct funding for the administration would leave more money for programs which are seriously underfunded. Right now, we receive only $84,000 per year in higher education and vocational education funds. With the increase in demand among Native Students entering College, we are able to accommodate only about half of the requests we receive every year. An increase in this area and funding to leave more money in the program would be a significant benefit to

all our tribal students. With the adoption of the every student succeeds act, we are looking for more funding and more flexibility in programs that would allow us to target the best areas to put our funding on these issues.

2. **Support the President's Budget FY 2017 Funding Investing in Tribally Driven Education.** The Presidents Proposed Budget for FY2017 provides for a significant increase in funding, $450 million dollars over the amount allocated last year, for the ED's Title I Program. This program is the largest K-12 grant program serving the Tribal Youth in Communities all across the United States. We at the Sac and Fox Nation feel that approval of this funding increase is critical to provide the support that low income schools need to bring their systems and the education of our youth into the future. It is especially important to us because Oklahoma has so many rural and small schools who struggle to provide their students with books and materials let alone high speed internet or access to research systems which can be critical to a well-rounded education. There has long been a disparity between the educations these rural schools can provide students. There is no reason for that disparity to exist. Those funds will also provide for supplies, books and materials that are currently unavailable in these rural communities because of funding concerns. With such a large portion of the Tribal Youth of the United States attending rural schools it is imperative that the funding levels reflect the needs that exist today.

3. **Increase Funding to Early Development and Preschool Services.** The Budget presented by the President is bold in its provision for $350 million dollars for preschool development grants, $100 Million over the levels from FY2016. This increase is both needed and forward thinking. As it has been said over and over, the youth are our future and if we cannot provide for them we will not be able to move forward. The Sac and Fox Nation is proud to offer early childhood development and head start programs to our Tribal Children throughout our jurisdiction. However, these programs are consistently underfunded and cannot provide for all of the demands that exist. Especially in Oklahoma communities which can be very rural there are not a lot of options for preschool or early education. We are proud of our programs, but they are located in major areas like Shawnee, Norman and Cushing Oklahoma. More funding and more opportunities in this area would allow programs like ours to grow and expand to make sure that all tribal youth are being served when it comes to early education.

II. NATIONAL REQUESTS – HEALTH AND HUMAN SERVICES

1. **Authorize mandatory funding and fully fund Contract Support Costs (CSC) for IHS**- The President's FY2017 Budget proposal fully funds the estimated need for CSC for Indian Health Services at $800 million, a significant increase over the levels of funding from FY2016. The estimated increase includes funding for new and expanded contracts and compacts. The Budget also requests that CSC be reclassified to a mandatory appropriation beginning in FY 2018. We at the Sac and Fox Nation strongly urge you to consider allocating all the requested funds in this area and making these appropriations mandatory and separate in the future. Our health and the access of our Native People to health care is a serious and major concern all around Indian Country. It is always prominent for us because we have so many people in rural communities who need greater access to medical care. Fully funding contract support costs and making them mandatory serves to take pressure off Tribal Nations who have a lack of certainty in their medical services when they are not sure if the funding will be there or not. When there is certainty, it allows programs like ours to expand both services and locations to provide better care within reach of our people.

2. ***Increase Funding to Social Services in Indian Country through Health and Human Services.*** The President's FY2017 Budget provides robust funding for the desperately needed social services in Indian Country. That budget is calling for a $204 million dollar increase of the funding level from 2016. These funds are being dedicated to the most critical issues currently facing Indian Country including $916 Million for HHS's Administration for Children and Families, $231 Million for Head Start Programs (which I previously addressed), $194 Million for Tribal TANF, $55 Million for Child Support, $212 Million for Child Care Programs, $106 Million for Child Welfare Programs, $53 Million for the Administration of Native Americans, and $55 million in SAMHSA to help reduce the ever worrisome increases in suicide among native youth. There is no shortage of things to say regarding each of these issues and why increasing their funding levels is critical. However, in order to be brief, I will simply say that these main issues are the ones we deal with every day on the ground in Tribal Governments. Tribal members are in desperate need of aid in these areas just to make their lives work. Our children are a critical resource that we must protect and the great work that is done by the Administration of Children and Families and all the Indian Child Welfare departments across the Nation should be properly funded. With the expansion of Indian Child Welfare, the BIA Guidelines and possible regulations these programs are in dire need of funding to ensure that they are running at the best capacity and efficiency possible. Protecting our Native youth from birth, through school and their trying years of finding themselves and their purpose is something that is paramount in our eyes. We strongly encourage you to consider this increase and to help us fight to make sure that critical services are reaching those who are most in need.

3. **Increase the Level of Funding for Programs like the Title VI Elders Program Food Delivery.** At the Sac and Fox Nation we are seeing a great increase in the number of elders who need help getting meals. However, not all of those elders are medically homebound. Some don't have transportation or vehicles, some have issues with being able to drive properly and others are too far from the kitchens where we serve are meals. We would like an increase in funding to this program and implementation of more flexibility or another program to include increasing issues like those we are seeing. With an increase in funding to these programs, more kitchens or meals centers could be opened to provide for the care of our growing population of elders. While this may seem small compared to the other major issues we know you are dealing with, it is no small issue to us. For a lot of our elder population, who may live in rural areas or communities, a meal delivery may provide them the only opportunity with human interaction on any given day. Moreover, it allows them to have a good, nutritious meal which is not a possibility for a lot of them on their own. Our meal delivery staff is critical to the health of our elders to make sure they are eating, taking care of themselves and can get help when it is needed. In a rural community, a meal delivery could save a life.

Thank you for allowing me to submit these requests on these FY 2017 Budgets.

NAEVR
National Alliance For
Eye And Vision Research
Serving as Friends of the National Eye Institute

1801 Rockville Pike, Suite 400
Rockville Maryland 20852
James Jorkasky, Executive Director
240-221-2905; jamesj@eyeresearch.org

WRITTEN TESTIMONY IN SUPPORT OF INCREASED FISCAL YEAR (FY) 2017 FUNDING FOR THE NATIONAL INSTITUTES OF HEALTH (NIH) AND THE NATIONAL EYE INSTITUTE (NEI)
LABOR, HEALTH AND HUMAN SERVICES, EDUCATION AND RELATED AGENCIES SUBCOMMITTEE OF THE HOUSE COMMITTEE ON APPROPRIATIONS
April 8, 2016

EXECUTIVE SUMMARY

NAEVR thanks Congress for its bipartisan action in FY2016 to increase NIH funding by $2 billion over FY2015, which is the largest actual dollar and percent increase since FY2003. To continue to rebuild NIH's discretionary funding base—especially as it has lost 22 percent of purchasing power since FY2003, in terms of constant dollars—and to ensure predictable and sustained funding, **NAEVR requests FY2017 appropriated NIH funding of at least $34.5 billion, a 7.5 percent increase reflecting 5 percent real growth above projected 2.5 percent biomedical inflation.**

NAEVR also thanks Congress for the $31 million National Eye Institute (NEI) increase over FY2015, especially since it reflects the first time in four years that NEI's operating budget exceeds that of the pre-sequester FY2012 level, albeit by a modest 0.8 percent. To continue to rebuild NEI's discretionary funding base—especially as it has lost 25 percent of purchasing power since FY2003, in terms of constant dollars—and to ensure predictable and sustained funding, **NAEVR requests FY2017 appropriated NEI funding of $770 million, also a 7.5 percent increase.**

NAEVR shares the concerns expressed by bipartisan Leaders and Members of the Appropriations Committee and the LHHS Appropriations Subcommittee regarding

the President's proposal to replace $1 billion of the NIH discretionary base funding with mandatory funding. NAEVR is especially concerned that the President proposes to not only flat-fund most of the Institutes and Centers (I/Cs), but achieve this through the use of mandatory funding. In the case of the NEI, its discretionary base would be reduced to $687 million, with the difference reflecting mandatory funding that would raise it to the flat-funded level of $708 million.

NAEVR looks forward to working with the appropriators to secure an increase of 5 percent real growth above inflation in FY2017 NIH and NEI funding as the next step in ensuring the security and momentum of the nation's biomedical research enterprise. We also stand ready to work with the authorizers on potential mechanisms to provide short-term "surge" funding to take advantage of the exceptional scientific opportunities now available to address current and emerging health challenges.

NEI'S BUDGET IS NOT KEEPING PACE AS THE BURDEN OF EYE DISEASE AND VISION IMPAIRMENT GROWS

NEI's FY2016 enacted funding of $715.9 million—reduced to a $708 million operating budget due to pass-throughs—reflects the first time in four fiscal years that NEI's operating budget exceeds that of the pre-sequester FY2012 funding level of $702 million. In the four years it has taken the NEI budget to grow a modest 0.8 percent, it has experienced the compounded loss of purchasing power due to biomedical inflation rates ranging from 2 to 2.5 percent. During that timeframe, NEI's operating budget was also reduced as a result of a transfer back to the NIH Office of AIDS Research (OAR) for funding of the successfully completed NEI-sponsored Studies of the Ocular Complications of AIDS (SOCA). Although OAR's funding to NEI was not committed

indefinitely, its return to NIH Central in the amounts of $5.6 million (FY2013), $6.9 million (FY2014), and $7.4 million (FY2015) had essentially cut NEI's budget further, resulting in a new baseline upon which future funding increases were calculated.

In June 2014, Prevent Blindness (PB) released a report entitled *The Future of Vision: Forecasting the Prevalence and Costs of Vision Problems,* which it commissioned from the University of Chicago's National Opinion Research Center (NORC). This report estimates the current annual cost (inclusive of direct and indirect costs) of vision disorders at $145 billion, an increase of $6 billion from the $139 billion estimate in PB's 2013 study entitled *Cost of Vision Problems: The Economic Burden of Vision Loss and Eye Disorders in the United States,* which also concluded that direct medical costs associated with vision disorders are the fifth highest—only less than heart disease, cancers, emotional disorders, and pulmonary conditions. PB's 2014 study projects that the total annual cost of vision disorders, which includes government, insurance, and patient costs, will grow to $373.2 billion in 2050 when expressed in 2014 dollars–which is $717 billion when adjusted for inflation. Of the $373.2 billion estimated 2050 costs, $154 billion or 41 percent will be borne by the federal government as the Baby-Boom generation ages into the Medicare program.

Current NEI funding of $708 million is still less than 0.5 percent of the $145 billion annual cost of vision disorders. The U.S. is spending only $2.20 per-person, per-year for vision research at the NEI, while the 2013 PB report estimates that the cost of treating low vision and blindness is at least $6,690 per-person, per-year.

The very health of the vision research community is also at stake. The convergence of past factors reducing NEI funding has affected both young and

seasoned investigators, threatened the continuity of research and the retention of trained staff, and made institutions more reliant on private bridge/philanthropic funding.

$770 MILLION FY2017 FUNDING ENABLES NEI TO PURSUE ITS *AUDACIOUS GOAL* OF RESTORING VISION

Despite past funding challenges, NEI has demonstrated leadership in identifying more than 500 genes associated with common and rare eye diseases. Its International Age-related Macular Degeneration (AMD) Genomics Consortium and its Glaucoma Human Genetics Collaboration Heritable Overall Operational Database (NEIGHBORHOOD) Consortium have each announced identification of additional gene variants associated with these leading causes of vision loss. Understanding the genetic bases of these eye diseases enables researchers and clinicians to identify those at risk and to potentially develop personalized treatment approaches, which is an NIH-wide initiative.

Among NEI's most exciting pursuits is the *Audacious Goals Initiative (AGI)*, which aims to restore vision within the next decade through regeneration of the retina by replacing cells that have been damaged by disease and injury and restoring their visual connections to the brain. The *AGI* builds upon discoveries from past investment in biomedical research, such as gene sequencing, gene therapy, and stem cell therapies, and combines these with new discoveries—such as imaging technologies that enable researchers to non-invasively view in real-time biological processes occurring in the retina at a cellular level—to develop new therapies for degenerative retinal disorders.

NEI has awarded the first set of grants associated with novel imaging technologies to help clinicians observe the function of individual neurons in human

patients and follow them over time as they test new therapies. It is proceeding with a second round of awards associated with identifying new factors that control regeneration and comparing the regenerative process among model organisms, rodents, and non-human primates.

As NEI Director Paul Sieving, M.D., Ph.D. noted in his February 2013 comments at the first *AGI* meeting:

> "Success would transform life for millions of people with eye and vision diseases. It would have major implications for medicine of the future, for vision diseases, and even beyond this, for neurological diseases."

These are ambitious goals that require sustained and predictable funding increases. Our nation's investment in vision health is an investment in its overall health. NEI's breakthrough research is a cost-effective investment, since it is leading to treatments and therapies that can ultimately delay, save, and prevent health expenditures, especially those associated with the Medicare and Medicaid programs. It can also increase productivity, help individuals to maintain their independence, and generally improve the quality of life—especially since vision loss is associated with increased depression and accelerated mortality.

In summary, NAEVR requests FY2017 NIH funding of at least $34.5 billion and NEI funding of $770 million—the latter to better understand the scientific bases upon which to save sight and restore vision.

NAEVR, which serves as the "Friends of the NEI," is a 501(c)4 non-profit advocacy coalition comprised of 55 professional (ophthalmology and optometry), patient and consumer, and industry organizations involved in eye and vision research. Visit NAEVR's Web site at www.eyeresearch.org.

Testimony
Kathryn Jedrziewski, PhD, Chair, Friends of the National Institute on Aging (NIA)
and
Deputy Director, University of Pennsylvania Institute on Aging
House Committee on Appropriations
Subcommittee on Labor, Health and Human Services
National Institutes of Health/National Institute on Aging
April 15, 2016

Chairman Cole, Ranking Member DeLauro, and members of the Committee, this testimony is being submitted on behalf of the Friends of the National Institute on Aging (FoNIA), www.friendsofnia.org, a coalition of more than 50 academic, patient-centered and non-profit organizations that supports the research and training missions of the National Institute on Aging (NIA). Considering the resources the federal government spends on the health care costs associated with age-related diseases, we feel it makes sound economic sense to increase federal resources for aging research. **Specifically, given the unique funding challenges facing the NIA, and the range of promising scientific opportunities in the field of aging research, the FoNIA recommends an additional $500 million in the FY 2017 National Institutes of Health (NIH) budget to support biomedical, behavioral and social sciences aging research efforts at the NIH.** We believe that this funding is the minimum essential to sustain research needed to make progress in attacking the chronic diseases that are driving significant increases in our national healthcare costs. **In addition, the FoNIA recommends a minimum increase of an additional $400 million in Alzheimer's Disease and Related Disorders (ADRD) research at NIH over the FY2016 enacted level.**

NIA's mission is urgent. The number of Americans aged 65 and older is growing at an unprecedented rate. By 2030, there will be 72 million Americans in this age group; more

than double the number from 2000. The number of "oldest old"—people age 85 or older—is expected to more than triple between 2010 and 2050. Age is a primary risk factor for many disabling diseases and conditions—most notably, Alzheimer's disease (AD). The NIA is the primary federal agency responsible for AD research. We know that over 5 million Americans aged 65 years and older may have AD with a predicted increase to 13.8 million by 2050. NIA's comprehensive AD research program spans the spectrum of discovery, from basic neuroscience through translational research and clinical application. The National Alzheimer's Plan, 2012 and 2015 Research Summits, and allocation of additional funds over the past several years have accelerated momentum in this field. Recommendations from the Research Summits have been incorporated into new Funding Opportunity Announcements (FOAs) that cover virtually every aspect of AD research including health disparities, caregiving, epidemiology, diagnosis and prediction, molecular and cellular mechanisms, brain aging and clinical trials.

Efforts in AD research have been bolstered by the advent of new technologies to generate and analyze enormous data sets. These new technologies have been particularly effective in identifying risk and protective genes for AD. Researchers can now access genome sequence data from the Alzheimer's Disease Sequencing Project (ADSP), a collaboration between the NIA and the National Human Genome Research Institute to facilitate identification of risk and protective genes. The opening of a new data sharing and analysis resource developed under AMP (Accelerating Medicines Partnership), the AMP-AD Knowledge Portal, and the release of the first wave of data

will enable large and complex biomedical datasets to be shared and analyzed. Researchers believe this approach will ultimately lead to selecting novel disease targets.

Because aging is the single biggest risk factor for the development of many chronic diseases, a better understanding of the basic biology of aging may open up new avenues for prevention and cures. Therefore investing in research on the basic biology of aging is a major priority for NIA. The establishment of the trans-NIH GeroScience Interest Group (GSIG) to facilitate discovery on the common risks and mechanisms behind age-related diseases and conditions has invigorated the field of basic geroscience. Recommendations from the 2013 GSIG Summit entitled "Advances in Geroscience: Impact on Healthspan and Chronic Disease" continue to energize researchers in this field.

Understanding that up to half of premature deaths in the United States are due to behavioral and social factors, NIA is committed to supporting basic behavioral and social research in aging. The NIA-supported Health and Retirement Study remains the world's premier multidisciplinary source of data on the health and well-being of older Americans, linking objective and subjective measures of health with information about retirement, economic status, family structure, personality, as well as health behaviors and service utilization. Funds from the American Recovery and Reinvestment Act facilitated expansion of the study, including genotyping DNA samples from participants. In FY 2016, research will be ongoing to take advantage of the newly available genetic

data to advance understanding of how genetic, behavioral and psychosocial factors affect health and well-being. NIA remains an active participant in the trans-NIH Science of Behavior Change initiative and the Basic Behavioral and Social Science Opportunity Network.

Personalized medicine is closer than ever to being realized for many aging-related diseases and conditions. One example involves AD – approaches to systems biology identifying complex genetic and molecular networks, such as AMP, will enable identification of molecular signatures and networks underlying the various disease processes that lead to symptoms associated with AD. NIA is also partnering with the Patient-Centered Outcomes Research Institute (PCORI) to test an individually-tailored injurious falls prevention strategy that includes a "fall care manager" in community health care systems. Falls are a key cause of disability in older people. Multiple chronic health conditions are common among older adults and another NIA initiative supports research to identify behavioral interventions, targeted at older adults with multiple chronic conditions, with high potential impact on health outcomes.

NIA also supports several innovative programs dedicated to training the next generation of aging researchers. These include the Paul Beeson Career Development Awards in Aging Research for outstanding clinician-scientists and the Butler-Williams Scholars Program, a "boot camp" for emerging investigators in aging research to prepare them to compete successfully for grant funding.

Despite the recent infusion of money targeted at ADRD research, which we greatly appreciate, NIA's current budget does not reflect the tremendous responsibility it has to meet the health research needs of a growing U.S. aging population. According to National Health Expenditure Data, in 2010 out of each healthcare dollar spent, 34 cents was spent on adults age 65 and older. Yet only 3.6 cents out of every dollar appropriated to NIH in 2010 went to support the work of NIA (NIH Almanac).

We recognize the tremendous fiscal challenges facing our nation and that there are many worthy, pressing priorities to support. However, we believe a commitment to the nation's aging population by making bold, wise investments in programs will benefit them and future generations. Investing in NIA is one of the smartest investments Congress can make.

Contact Information:
Kathryn Jedrziewski, PhD, Chair
Friends of the National Institute on Aging (FoNIA)
Deputy Director, University of Pennsylvania Institute on Aging
jedrzmk@mail.med.upenn.edu

National League
for **Nursing**

Testimony Regarding Fiscal Year 2017 Appropriations for the Title VIII Nursing Workforce Development Programs
April 15, 2016

Submitted by: Anne R. Bavier, PhD, RN, FAAN, President, National League for Nursing
Dean, University of Texas at Arlington College of Nursing

Beverly Malone, PhD, RN, FAAN, Chief Executive Officer, National League for Nursing

To: Subcommittee on Labor, Health & Human Services, Education, and Related Agencies, Committee on Appropriations, US House of Representatives

The NLN promotes excellence in nursing education to build a strong and diverse nursing workforce to advance the health of the nation and the global community. The League represents more than 1,200 nursing schools, 40,000 members, and 25 regional constituent leagues. **The NLN urges the subcommittee to fund the Health Resources and Services Administration's (HRSA) Title VIII nursing workforce development programs at $244 million in FY 2017. This amount is equal to the FY 2010 funding level for the Title VIII programs.**

Nursing Education

Health inequities, inflated costs, and poor health care outcomes are intensifying because of today's shortfall of appropriately prepared registered nurses (RNs) and licensed vocational/practical nurses (LVN/LPNs). With 4.6 million active, licensed RNs/LPNs, nurses are the primary professionals delivering quality health care in the nation. According to the Bureau of Labor Statistics (BLS), the RN workforce is projected to grow by 16 percent from 2014-2024, resulting in 1,088,400 job openings due to growth and replacement needs. BLS also calculates the LVN/LPN workforce will grow by 16.3 percent resulting in 322,200 job openings during the same timeframe. This increase is fueled by an increased demand for health care services for the aging population. Nurses will also be needed to educate and care for patients with various chronic conditions, such as arthritis, dementia, diabetes, and obesity. The situation is further affected by the needed replacement of some 439,300 jobs vacated by RNs and 117,000 vacated by LVN/LPNs who will leave the profession and/or retire by 2024.

The nursing shortage continues to outpace the level of federal resources allocated by Congress to help alleviate it. Appropriations for nursing education are inconsistent with the health care reality facing our nation today. For the last 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, health care in underserved communities. The Title VIII programs are fundamental to the infrastructure delivering quality, cost-effective health care. The NLN applauds the subcommittee's bipartisan efforts to recognize that a strong nursing workforce is essential to health policy that provides high-value care for every dollar invested in capacity building for a 21st century nurse workforce. Insufficient federal investments in the nursing workforce are a short-sighted course of action that further jeopardizes access to, and the quality of, the nation's health care delivery. Absent consistent support, slight boosts to Title VIII programs will not fulfill the expectation of generating quality health outcomes, nor will episodic increases in funding fill the gap generated by a 15-year nurse and nurse faculty shortage felt throughout the U.S. health system.

THE NURSE PIPELINE AND EDUCATION CAPACITY

Although the recession resulted in some stability in the short-term for the nurse workforce, policy makers must not lose sight of the long-term growing demand for nurses in their districts and states. As the United States tackles the workforce shortage that exacerbates the stress in the health care system, nursing programs across the country are rejecting qualified candidates because there is not enough faculty to teach them. The percentage of LPN/LVN pre-licensure programs that turned away qualified applicants dropped by 11 percent according to the NLN's survey of schools of nursing for academic year 2013-2014. The percentage for BSN programs remained unchanged between 2012 and 2014, while the percentage for BSRN (RN to BSN), masters, and doctorate programs increased by 6 percent, 8 percent, and 4 percent, respectively. If BSN programs remain the same as from 2012 to 2014, this could have a potential impact on the Institute of Medicine's (IOM) recommendation in ***The Fu-***

ture of Nursing: Leading Change, Advancing Health (2011) for an increase in the proportion of nurses with baccalaureate degrees from 50 to 80 percent by 2020.

While the proportion of programs that turn away qualified applicants in prelicensure programs is declining, the NLN survey still indicates that a number of qualified applications are being rejected due to various constraints encountered by nursing programs. A lack of clinical placement settings continues to be a critical constraint as well as lack of faculty to expanding the capacity of nursing programs in almost all programs. NLN research on America's nearly 60,000 nurse educators shows that a core cause of the shortage is an aging and overworked faculty who earn less than nurses entering clinical practice. Sixty percent of all full-time nurse faculty members are 45- to 60-years old. Fifty-five percent of nurse faculty say they are likely to leave academic nursing by 2020. BLS projects a need of 25,400 new nursing instructors by 2024 due to the expected increase in demand as well as the expected retirement of 12,200 current faculty members.

EQUALLY PRESSING IS LACK OF DIVERSITY

Besides representing an untapped talent pool to remedy the nationwide nursing shortage, diversity in nursing is essential to developing a health care system that understands and addresses the needs of our rapidly changing population. Our nation is enriched by cultural complexity – 37 percent of our population identify as racial and ethnic minorities. Yet diversity eludes the nursing student and nurse educator populations. Minorities only constitute 28 percent of the student population and males only 15 percent of pre-licensure RN students. A survey of nurse educators conducted by the NLN and the Carnegie Foundation's Preparation for the Professions Program found that only 7 percent of nurse educators were minorities compared with 16 percent of all U.S. faculty. The lack of faculty diversity limits nursing schools' ability to deliver culturally appropriate health professions education. Workforce diversity is needed where research indicates that factors such as societal biases and stereotyping, communication barriers, limited cultural sensitivity and competence, and system and organizational determinants contribute to healthcare inequities.

Title VIII Federal Funding Reality

Today's undersupply of appropriately prepared nurses and nurse faculty, as well as the projected loss of experienced nurses over the next decade, does not bode well for our nation. The Title VIII nursing workforce development programs are a comprehensive system of capacity-building strategies that provide students and schools of nursing with grants to strengthen education programs, including faculty recruitment and retention efforts, facility and equipment acquisition, clinical lab enhancements, loans, scholarships, and services that enable students to overcome obstacles to completing their nursing education programs. HRSA's Title VIII data below from the agency's FY 2017 budget justification of estimates provide a perspective on current federal investments.

The **Advanced Nursing Education (ANE)** program supports infrastructure grants to schools of nursing for advanced practice programs preparing nurse-midwives, nurse anesthetists, nurse practitioners, clinical nurse specialists, nurse administrators, nurse educators, public health nurses, or other advanced level nurses. In academic year 2014-2015, ANE program grantees trained 8,735 nursing students and produced 2,148 graduates. In addition, 30 percent of students trained were underrepresented minorities and/or from disadvantaged backgrounds.

Nursing Workforce Diversity (NWD) grants increase educational opportunities for individuals from disadvantaged backgrounds (including racial and ethnic minorities underrepresented in nursing) through scholarship or stipend support, pre-entry preparation, and retention activities. In academic year 2014-2015, the number of nursing program students trained was 4,400.

Nurse Education, Practice, Quality, and Retention Grants (NEPQR) address the critical nursing shortage via projects to expand the nursing pipeline, promote career mobility, provide continuing education, and support retention. The NEPQR program funded the Veterans' Bachelor of Science in Nursing (VBSN) program and made awards to 17 schools. Four hundred seventy-two veterans were enrolled in BSN degree programs and 82 graduated with a BSN degree. It is estimated that 33 percent of participating veterans were underrepresented

minorities in the field of nursing, and 24 percent reported coming from a financially and/or educationally disadvantaged background.

The **Nurse Faculty Loan Program (NFLP)** supports the establishment and operation of a loan fund at participating schools of nursing to assist nurses in completing their graduate education to become qualified nurse faculty. In academic year 2014-2015, the NFLP supported 2,399 students pursuing faculty preparation. Twenty percent of students who received a loan reported coming from a disadvantaged background and nearly 25 percent of students are considered underrepresented minorities in their prospective professions.

The **NURSE Corps Scholarship and Loan Repayment Program (NURSE Corps)** offers to individuals, who are enrolled or accepted for enrollment as full-time or part-time nursing students, the opportunity to apply for funds. The NURSE Corps repays up to 85 percent of nursing student loans in return for at least three years of practice in a designated nursing shortage area. In FY 2015, the NURSE Corps loan repayment program made 590 loan repayment awards and 319 continuation awards. The NURSE Corps scholarship program made 257 new scholarship awards and 12 continuation awards during the same time period.

The NLN urges the subcommittee to fund the Title VIII nursing workforce development programs at the FY 2010 funding level of $244 million in FY 2017.

NLN Contact Information:
Christine Murphy
Director of Public Policy and Advocacy
National League for Nursing
2600 Virginia Avenue, NW, 8th Floor
Washington, D.C. 20037
Phone: 202-909-2533
Email: cmurphy@nln.org

Scott Robbins

Program Director

Independence Northwest; Center for Independent Living of Northwestern Connecticut

I am writing to support the National Council on Independent Living's request for Congress to reaffirm your commitment to the more than 57 million Americans disabilities by increasing funding in the HHS appropriations for Centers for Independent Living (CILs). I am asking that you increase funding by $200 million, for a total of $301 million for the Independent Living line item in FY 2017.

CILs are cross-disability, non-residential, community-based, nonprofit organizations that are designed and operated by individuals with disabilities. CILs are unique in that they are directly governed and staffed by people with all types of disabilities, including people with mental, physical, sensory, cognitive, and developmental disabilities. Each of the 365 federally funded centers provides five core services: information and referral, individual and systems advocacy, peer support, independent living skills training, and transition services, which were added with the passage of the Workforce Innovation and Opportunity Act (WIOA). From 2012-2014, CILs provided the core services to nearly 5 million people with disabilities, and provided additional services such as housing assistance, transportation, personal care attendants, and employment services to hundreds of thousands of individuals. During this same period, prior to transition being added as a core service, CILs transitioned 13,030 people with disabilities from nursing homes and other institutions into the community.

Transition services were added as a fifth core service with the 2014 reauthorization of the Rehabilitation Act within the Workforce Innovation and Opportunity Act. Transition services include the transition of individuals with significant disabilities from nursing homes and other institutions to home and community-based residences with appropriate supports and services, assistance to individuals with significant disabilities at risk of entering institutions to remain in the community, and the transition of youth with significant disabilities to postsecondary life. This core service is vital to achieving full participation for people with disabilities.

Every day, CILs are fighting to ensure that people with disabilities gain and maintain control over our own lives. We know that this cannot occur when people reside in institutional settings. Opponents of deinstitutionalization say that allowing people with disabilities to live in the community will result in harm. We know that the 13,030 people with disabilities who CILs successfully transitioned out of nursing homes and institutions from 2012-2014 prove otherwise. Additionally, when services are delivered in an individual's home, the result is a tremendous cost savings to Medicaid, Medicare, and states. Community-based services enable people with disabilities to become less reliant on long-term government supports, and they are significantly less expensive than nursing home placements. We are grateful that Congress demonstrated their understanding and support for community-based services when WIOA was passed and transition was added as a fifth core service.

Since transition services were added as a core service, the need for funding is critical. Moreover, CILs need additional funding to restore the devastating cuts to the Independent Living program, make up for inflation costs, and address the increased demand for independent living services. In

2016, the Independent Living Program is receiving $2.5 million less in funding than it was in 2010. It is simply not possible to meet the increasing demand for services and effectively provide transition services without additional funding. Increased funding should be reinvested from the billions currently spent to keep people with disabilities in costly Medicaid nursing homes and institutions and out of mainstream society.

Centers for Independent Living play a crucial role in the lives of people with disabilities, and work tirelessly to ensure that people with disabilities have a real choice in where and how they live, work, and participate in the community. Additionally, CILs are an excellent service and a bargain for America, keeping people engaged with their communities and saving taxpayer money. NCIL is dedicated to increasing the availability of the invaluable and extremely cost-effective services CILs provide, and they have submitted written testimony with a similar request. I strongly support NCIL's testimony.

Global Health Technologies Coalition Outside Witness Testimony for the Record
Subcommittee on Labor, Health and Human Services, Education and Related Agencies
April 11, 2016
Erin Will Morton, Coalition Director, Global Health Technologies Coalition

Chairman Cole, Ranking Member DeLauro, and members of the Committee, thank you for the opportunity to provide testimony on the fiscal year 2017 appropriations funding for the National Institutes of Health (NIH) and the Centers for Disease Control and Prevention (CDC). We appreciate your leadership in promoting the importance of international development, in particular global health. I am submitting this testimony on behalf of the Global Health Technologies Coalition (GHTC), a group of more than 25 nonprofit organizations working together to advance US policies that can accelerate the development of new global health innovations—including new vaccines, drugs, diagnostics, microbicides, multipurpose prevention technologies, and other tools—to combat global health diseases and conditions.

GHTC members strongly believe that in order to meet the world's most pressing global health needs, it is critical to invest in research today so that the most effective health solutions are available now and in the future. Sustainable investment in research and development (R&D) for a broad range of neglected diseases and health conditions is critical to tackling both endemic and emerging global health challenges that impact people around the world and at home in the United States. This need is particularly acute now, as the world is facing an increasing Zika epidemic and is still recovering from the 2014 Ebola outbreak—two diseases about which we knew little, and have no approved tools to diagnose, prevent, or treat.

My testimony reflects the needs expressed by our member organizations, which work with a wide variety of partners to develop new and more effective lifesaving technologies, for the world's most pressing health issues. We strongly urge the Committee to continue its established support for global health R&D by:

1) Sustaining and supporting US investment in global health research and product development and fully funding the NIH at a level of at least US$34.5 billion, and providing robust funding for the CDC, with $457 million for the CDC Center for Global Health, and $629.49 million for the CDC National Center for Emerging Zoonotic and Infectious Diseases (NCEZID).
2) Urging leaders at the NIH, CDC, the Food and Drug Administration, and other entities within the US Department of Health and Human Services, like the Office of Global Affairs, the Biomedical Advanced Research and Development Authority, and the National Center for Advancing Translational Science (NCATS), to join leaders of other US agencies to develop a cross-US government global health R&D strategy to ensure that US investments in global health research are efficient, coordinated, and streamlined.

Critical need for new global health tools

While we have made tremendous gains in global health over the past fifteen years, millions of people around the world are still threatened by HIV/AIDS, tuberculosis (TB), malaria, and other neglected diseases and health conditions. In 2014, TB killed 1.5 million people, surpassing deaths from HIV/AIDS. Sub-Saharan Africa saw 1.4 million new HIV infections. Half the global population remains at risk for malaria and drug-resistant strains are growing. Maternal mortality is 14 times greater in under-resourced regions than developed

countries. One out of every 12 children in sub-Saharan Africa dies before the age of five, often from vaccine-preventable and other communicable diseases. These figures highlight the tremendous global health challenges that still remain and the need for sustained investment in global health research to deliver new tools to combat endemic and emerging threats.

New tools and technologies are critical, 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 the tools needed to prevent, diagnose, and treat many neglected diseases. While it is important to work to increase access to proven, existing drugs, vaccines, diagnostics, and other health tools, it is just as critical to invest in the development of next generation tools to fight existing and emerging disease threats. Particularly in our era of globalization where diseases know no borders, investments today in global health innovations for existing global health threats and new and emerging infections will mean millions of future lives saved—at home and around the world.

Research and US global health efforts

The United States is at the forefront of innovation in global health, with the NIH and CDC leading much of our global health research.

NIH

The groundbreaking science conducted at the NIH has helped make the United States a global leader in medical research. Not only does NIH research lead to novel medical technologies for American patients, but it also fuels important discoveries and innovative applications of tools that help address both longstanding and emerging global health challenges.

Within the NIH, the National Institute of Allergy and Infectious Diseases, the Office of AIDS Research, the Fogarty International Center, and NCATS all play critical roles in developing new health technologies that save lives around the world and at home in the United States. Recent activities have led to the development of new tools to combat neglected diseases, including vaccines for dengue fever and trachoma; new drugs to treat malaria and TB; and multiple projects to develop diagnostics, vaccines, and treatments for Ebola, including the development of ZMapp and the development and testing of Ebola vaccine candidates. NIH Director Dr. Francis Collins, recognizes the critical role the agency plays in global health R&D, and has named global health as one of the agency's top five priorities.

For this important work to continue, the NIH needs adequate funding. We recognize and are grateful for Congress' work to bolster funding for the critical programs supported by NIH. However, Dr. Collins recently noted that the Bureau of Economic Analysis has calculated that due to rising costs of biomedical research expenses, the NIH has had a 23 percent drop in purchasing power since 2003. 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.

It is also important to stress the critical role that NCATS plays in translating basic research for neglected diseases into urgently needed tools and technologies. R&D conducted at NCATS has contributed to the development of early stage compounds to treat diseases including Chagas disease, schistosomiasis, giardia, and HIV/AIDS. We remain concerned that NCATS is the only NIH center limited by statute from supporting clinical trials beyond phase IIA. There is little risk of NCATS duplicating the global health activities of private industry, as this sector does not typically target neglected diseases due to limited commercial markets. We hope you will work to remove this statutory barrier and extend NCATS' ability to conduct trials through stage III—the final pre-market stage where safety and efficacy of a treatment are tested in large groups of individuals.

CDC

The CDC also makes significant contributions to global health research. The CDC's ability to respond to disease outbreaks, such as the current Zika outbreak and 2014 Ebola Virus Disease epidemic in West Africa, is essential to protecting the health of citizens both at home and abroad. The work of its scientists has led to major advancements against devastating diseases, including the eradication of smallpox and early identification of HIV/AIDS.

Within the CDC, the Center for Global Health and NCEZID are critical to global health R&D and global health security efforts. Important work at NCEZID includes innovative technologies to provide a rapid diagnostic test for the Ebola virus; a new vaccine to improve rabies control; a new and more accurate diagnostic test for dengue virus; and coordination of the National Strategy for Combating Antibiotic Resistant Bacteria, focused on preventing, detecting, and controlling outbreaks of antibiotic resistant pathogens, such as drug-resistant tuberculosis. Programs at CDC's Center for Global Health—including the Global HIV/AIDS, Global Immunization, Parasitic Diseases and Malaria, Global Disease Detection and Emergency Response, and Global Public Health Capacity Development programs—have also yielded tremendous results in the development of new vaccines, drugs, microbicides, and other tools to combat HIV/AIDS, TB, malaria, and lesser known diseases like leishmaniasis, dengue fever, and schistosomiasis.

In addition, the CDC works to implement the Global Health Security Agenda—a whole-of-government initiative that works to build capacity in 30 low- and middle-income countries to detect global health risks rapidly. We urge your support for this initiative alongside the vital work already ongoing at the Center for Global Health and NCEZID.

Innovation as a smart economic choice

Global health R&D brings lifesaving tools to those who need them most. However, the benefits of investing in these research efforts are much broader than preventing and treating disease. Global health R&D is also a smart economic investment in the United States, where it drives job creation, spurs business activity, and benefits academic institutions. Biomedical research, including global health, is a $100 billion enterprise in the United States. Sixty-four cents of every US dollar invested in global health R&D goes directly to US-based researchers. As just one example of the many states positively impacted by global health R&D, the global health industry in Washington State includes 168 global health organizations, 54 percent of

whom work on global health technology and devices. This industry directly accounts for $5.8 billion in output and provided 12,620 direct global health jobs in the state. In addition, investments in global health R&D today can help save significant money in the future. New therapies to treat drug-resistant TB, for example, have the potential to reduce the price of TB treatment by 90 percent and cut health system costs significantly.

Smart investments in medical research in the past have yielded lifesaving breakthroughs for global health diseases, as well as important advances in diseases endemic to the United States. We must continue to build on those investments, and turn discoveries into new vaccines, drugs, tests, and other tools. Now more than ever, Congress must make smart budget decisions. Global health research that improves the lives of people around the world—while at the same time supporting US interests, creating jobs, and spurring economic growth at home—is a win-win. On behalf of the members of the GHTC, I would like to extend my gratitude to the Committee for the opportunity to submit written testimony for the record.

Name: Sheila Thomas

Title: Executive Director

Institutional Affiliation: LILA (Lane Independent Living Alliance)

20 E 13th Avenue, Eugene OR 97401

Phone: 541-607-7020

Email: sthomas@lilaoregon.org

I am writing to support the National Council on Independent Living's request for Congress to reaffirm your commitment to the more than 57 million Americans disabilities by increasing funding in the HHS appropriations for Centers for Independent Living (CILs). I am asking that you increase funding by $200 million, for a total of $301 million for the Independent Living line item in FY 2017.

CILs are cross-disability, non-residential, community-based, nonprofit organizations that are designed and operated by individuals with disabilities. CILs are unique in that they are directly governed and staffed by people with all types of disabilities, including people with mental, physical, sensory, cognitive, and developmental disabilities. Each of the 365 federally funded centers provides five core services: information and referral, individual and systems advocacy, peer support, independent living skills training, and transition services, which were added with the passage of the Workforce Innovation and Opportunity Act (WIOA). From 2012-2014, CILs provided the core services to nearly 5 million people with disabilities, and provided additional services such as housing assistance, transportation, personal care attendants, and employment services to hundreds of thousands of individuals. During this same period, prior to transition being added as a core service, CILs transitioned 13,030 people with disabilities from nursing homes and other institutions into the community.

Transition services were added as a fifth core service with the 2014 reauthorization of the Rehabilitation Act within the Workforce Innovation and Opportunity Act. Transition services include the transition of individuals with significant disabilities from nursing homes and other institutions to home and community-based residences with appropriate supports and services, assistance to individuals with significant disabilities at risk of entering institutions to remain in the community, and the transition of youth with significant disabilities to postsecondary life. This core service is vital to achieving full participation for people with disabilities.

Every day, CILs are fighting to ensure that people with disabilities gain and maintain control over our own lives. We know that this cannot occur when people reside in institutional settings. Opponents of deinstitutionalization say that allowing people with disabilities to live in the community will result in harm. We know that the 13,030 people with disabilities who CILs successfully transitioned out of nursing homes and institutions from 2012-2014 prove otherwise. Additionally, when services are delivered in an individual's home, the result is a tremendous cost

savings to Medicaid, Medicare, and states. Community-based services enable people with disabilities to become less reliant on long-term government supports, and they are significantly less expensive than nursing home placements. We are grateful that Congress demonstrated their understanding and support for community-based services when WIOA was passed and transition was added as a fifth core service.

Since transition services were added as a core service, the need for funding is critical. Moreover, CILs need additional funding to restore the devastating cuts to the Independent Living program, make up for inflation costs, and address the increased demand for independent living services. In 2016, the Independent Living Program is receiving $2.5 million less in funding than it was in 2010. It is simply not possible to meet the increasing demand for services and effectively provide transition services without additional funding. Increased funding should be reinvested from the billions currently spent to keep people with disabilities in costly Medicaid nursing homes and institutions and out of mainstream society.

Centers for Independent Living play a crucial role in the lives of people with disabilities, and work tirelessly to ensure that people with disabilities have a real choice in where and how they live, work, and participate in the community. Additionally, CILs are an excellent service and a bargain for America, keeping people engaged with their communities and saving taxpayer money. NCIL is dedicated to increasing the availability of the invaluable and extremely cost-effective services CILs provide, and they have submitted written testimony with a similar request. I strongly support NCIL's testimony.

Curtis Raines
Executive Director
Center for Independent Living

I am writing to support the National Council on Independent Living's request for Congress to reaffirm your commitment to the more than 57 million Americans disabilities by increasing funding in the HHS appropriations for Centers for Independent Living (CILs). I am asking that you increase funding by $200 million, for a total of $301 million for the Independent Living line item in FY 2017.

CILs are cross-disability, non-residential, community-based, nonprofit organizations that are designed and operated by individuals with disabilities. CILs are unique in that they are directly governed and staffed by people with all types of disabilities, including people with mental, physical, sensory, cognitive, and developmental disabilities. Each of the 365 federally funded centers provides five core services: information and referral, individual and systems advocacy, peer support, independent living skills training, and transition services, which were added with the passage of the Workforce Innovation and Opportunity Act (WIOA). From 2012-2014, CILs provided the core services to nearly 5 million people with disabilities, and provided additional services such as housing assistance, transportation, personal care attendants, and employment services to hundreds of thousands of individuals. During this same period, prior to transition being added as a core service, CILs transitioned 13,030 people with disabilities from nursing homes and other institutions into the community.

Transition services were added as a fifth core service with the 2014 reauthorization of the Rehabilitation Act within the Workforce Innovation and Opportunity Act. Transition services include the transition of individuals with significant disabilities from nursing homes and other institutions to home and community-based residences with appropriate supports and services, assistance to individuals with significant disabilities at risk of entering institutions to remain in the community, and the transition of youth with significant disabilities to postsecondary life. This core service is vital to achieving full participation for people with disabilities.

Every day, CILs are fighting to ensure that people with disabilities gain and maintain control over our own lives. We know that this cannot occur when people reside in institutional settings. Opponents of deinstitutionalization say that allowing people with disabilities to live in the community will result in harm. We know that the 13,030 people with disabilities who CILs successfully transitioned out of nursing homes and institutions from 2012-2014 prove otherwise. Additionally, when services are delivered in an individual's home, the result is a tremendous cost savings to Medicaid, Medicare, and states. Community-based services enable people with disabilities to become less reliant on long-term government supports, and they are significantly less expensive than nursing home placements. We are grateful that Congress demonstrated their understanding and support for community-based services when WIOA was passed and transition was added as a fifth core service.

Since transition services were added as a core service, the need for funding is critical. Moreover, CILs need additional funding to restore the devastating cuts to the Independent Living program, make up for inflation costs, and address the increased demand for independent living services. In 2016, the Independent Living Program is receiving $2.5 million less in funding than it was in 2010. It is simply not possible to meet the increasing demand for services and effectively provide transition services without additional funding. Increased funding should be reinvested from the billions currently spent to keep people with disabilities in costly Medicaid nursing homes and institutions and out of mainstream society.

Centers for Independent Living play a crucial role in the lives of people with disabilities, and work tirelessly to ensure that people with disabilities have a real choice in where and how they live, work, and participate in the community. Additionally, CILs are an excellent service and a bargain for America, keeping people engaged with their communities and saving taxpayer money. NCIL is dedicated to increasing the availability of the invaluable and extremely cost-effective services CILs provide, and they have submitted written testimony with a similar request. I strongly support NCIL's testimony.

Patt Kosier

Executive Director

Center for Independence

I am writing to support the National Council on Independent Living's request for Congress to reaffirm your commitment to the more than 57 million Americans disabilities by increasing funding in the HHS appropriations for Centers for Independent Living (CILs). I am asking that you increase funding by $200 million, for a total of $301 million for the Independent Living line item in FY 2017.

CILs are cross-disability, non-residential, community-based, nonprofit organizations that are designed and operated by individuals with disabilities. CILs are unique in that they are directly governed and staffed by people with all types of disabilities, including people with mental, physical, sensory, cognitive, and developmental disabilities. Each of the 365 federally funded centers provides five core services: information and referral, individual and systems advocacy, peer support, independent living skills training, and transition services, which were added with the passage of the Workforce Innovation and Opportunity Act (WIOA). From 2012-2014, CILs provided the core services to nearly 5 million people with disabilities, and provided additional services such as housing assistance, transportation, personal care attendants, and employment services to hundreds of thousands of individuals. During this same period, prior to transition being added as a core service, CILs transitioned 13,030 people with disabilities from nursing homes and other institutions into the community.

Transition services were added as a fifth core service with the 2014 reauthorization of the Rehabilitation Act within the Workforce Innovation and Opportunity Act. Transition services include the transition of individuals with significant disabilities from nursing homes and other institutions to home and community-based residences with appropriate supports and services, assistance to individuals with significant disabilities at risk of entering institutions to remain in the community, and the transition of youth with significant disabilities to postsecondary life. This core service is vital to achieving full participation for people with disabilities.

Every day, CILs are fighting to ensure that people with disabilities gain and maintain control over our own lives. We know that this cannot occur when people reside in institutional settings. Opponents of deinstitutionalization say that allowing people with disabilities to live in the community will result in harm. We know that the 13,030 people with disabilities who CILs successfully transitioned out of nursing homes and institutions from 2012-2014 prove otherwise. Additionally, when services are delivered in an individual's home, the result is a tremendous cost savings to Medicaid, Medicare, and states. Community-based services enable people with disabilities to become less reliant on long-term government supports, and they are significantly less expensive than nursing home placements. We are grateful that Congress demonstrated their understanding and support for community-based services when WIOA was passed and transition was added as a fifth core service.

Since transition services were added as a core service, the need for funding is critical. Moreover, CILs need additional funding to restore the devastating cuts to the Independent Living program, make up for inflation costs, and address the increased demand for independent living services. In

2016, the Independent Living Program is receiving $2.5 million less in funding than it was in 2010. It is simply not possible to meet the increasing demand for services and effectively provide transition services without additional funding. Increased funding should be reinvested from the billions currently spent to keep people with disabilities in costly Medicaid nursing homes and institutions and out of mainstream society.

Centers for Independent Living play a crucial role in the lives of people with disabilities, and work tirelessly to ensure that people with disabilities have a real choice in where and how they live, work, and participate in the community. Additionally, CILs are an excellent service and a bargain for America, keeping people engaged with their communities and saving taxpayer money. NCIL is dedicated to increasing the availability of the invaluable and extremely cost-effective services CILs provide, and they have submitted written testimony with a similar request. I strongly support NCIL's testimony.

Name: Donna Smith

Title: Program Director, Appalachian Independence Center

I am writing to support the National Council on Independent Living's request for Congress to reaffirm your commitment to the more than 57 million Americans disabilities by increasing funding in the HHS appropriations for Centers for Independent Living (CILs). I am asking that you increase funding by $200 million, for a total of $301 million for the Independent Living line item in FY 2017.

CILs are cross-disability, non-residential, community-based, nonprofit organizations that are designed and operated by individuals with disabilities. CILs are unique in that they are directly governed and staffed by people with all types of disabilities, including people with mental, physical, sensory, cognitive, and developmental disabilities. Each of the 365 federally funded centers provides five core services: information and referral, individual and systems advocacy, peer support, independent living skills training, and transition services, which were added with the passage of the Workforce Innovation and Opportunity Act (WIOA). From 2012-2014, CILs provided the core services to nearly 5 million people with disabilities, and provided additional services such as housing assistance, transportation, personal care attendants, and employment services to hundreds of thousands of individuals. During this same period, prior to transition being added as a core service, CILs transitioned 13,030 people with disabilities from nursing homes and other institutions into the community.

Transition services were added as a fifth core service with the 2014 reauthorization of the Rehabilitation Act within the Workforce Innovation and Opportunity Act. Transition services include the transition of individuals with significant disabilities from nursing homes and other institutions to home and community-based residences with appropriate supports and services, assistance to individuals with significant disabilities at risk of entering institutions to remain in the community, and the transition of youth with significant disabilities to postsecondary life. This core service is vital to achieving full participation for people with disabilities.

Every day, CILs are fighting to ensure that people with disabilities gain and maintain control over our own lives. We know that this cannot occur when people reside in institutional settings. Opponents of deinstitutionalization say that allowing people with disabilities to live in the community will result in harm. We know that the 13,030 people with disabilities who CILs successfully transitioned out of nursing homes and institutions from 2012-2014 prove otherwise. Additionally, when services are delivered in an individual's home, the result is a tremendous cost savings to Medicaid, Medicare, and states. Community-based services enable people with disabilities to become less reliant on long-term government supports, and they are significantly less expensive than nursing home placements. We are grateful that Congress demonstrated their understanding and support for community-based services when WIOA was passed and transition was added as a fifth core service.

Since transition services were added as a core service, the need for funding is critical. Moreover, CILs need additional funding to restore the devastating cuts to the Independent Living program, make up for inflation costs, and address the increased demand for independent living services. In

2016, the Independent Living Program is receiving $2.5 million less in funding than it was in 2010. It is simply not possible to meet the increasing demand for services and effectively provide transition services without additional funding. Increased funding should be reinvested from the billions currently spent to keep people with disabilities in costly Medicaid nursing homes and institutions and out of mainstream society.

Centers for Independent Living play a crucial role in the lives of people with disabilities, and work tirelessly to ensure that people with disabilities have a real choice in where and how they live, work, and participate in the community. Additionally, CILs are an excellent service and a bargain for America, keeping people engaged with their communities and saving taxpayer money. NCIL is dedicated to increasing the availability of the invaluable and extremely cost-effective services CILs provide, and they have submitted written testimony with a similar request. I strongly support NCIL's testimony.

Sincerely,
Donna Smith

Name: Sheila Thomas

Title: Executive Director

Institutional Affiliation: LILA (Lane Independent Living Alliance)

I am writing to support the National Council on Independent Living's request for Congress to reaffirm your commitment to the more than 57 million Americans disabilities by increasing funding in the HHS appropriations for Centers for Independent Living (CILs). I am asking that you increase funding by $200 million, for a total of $301 million for the Independent Living line item in FY 2017.

CILs are cross-disability, non-residential, community-based, nonprofit organizations that are designed and operated by individuals with disabilities. CILs are unique in that they are directly governed and staffed by people with all types of disabilities, including people with mental, physical, sensory, cognitive, and developmental disabilities. Each of the 365 federally funded centers provides five core services: information and referral, individual and systems advocacy, peer support, independent living skills training, and transition services, which were added with the passage of the Workforce Innovation and Opportunity Act (WIOA). From 2012-2014, CILs provided the core services to nearly 5 million people with disabilities, and provided additional services such as housing assistance, transportation, personal care attendants, and employment services to hundreds of thousands of individuals. During this same period, prior to transition being added as a core service, CILs transitioned 13,030 people with disabilities from nursing homes and other institutions into the community.

Transition services were added as a fifth core service with the 2014 reauthorization of the Rehabilitation Act within the Workforce Innovation and Opportunity Act. Transition services include the transition of individuals with significant disabilities from nursing homes and other institutions to home and community-based residences with appropriate supports and services, assistance to individuals with significant disabilities at risk of entering institutions to remain in the community, and the transition of youth with significant disabilities to postsecondary life. This core service is vital to achieving full participation for people with disabilities.

Every day, CILs are fighting to ensure that people with disabilities gain and maintain control over our own lives. We know that this cannot occur when people reside in institutional settings. Opponents of deinstitutionalization say that allowing people with disabilities to live in the community will result in harm. We know that the 13,030 people with disabilities who CILs successfully transitioned out of nursing homes and institutions from 2012-2014 prove otherwise. Additionally, when services are delivered in an individual's home, the result is a tremendous cost savings to Medicaid, Medicare, and states. Community-based services enable people with disabilities to become less reliant on long-term government supports, and they are significantly less expensive than nursing home placements. We are grateful that Congress demonstrated their understanding and support for community-based services when WIOA was passed and transition was added as a fifth core service.

Since transition services were added as a core service, the need for funding is critical. Moreover, CILs need additional funding to restore the devastating cuts to the Independent Living program, make up for inflation costs, and address the increased demand for independent living services. In 2016, the Independent Living Program is receiving $2.5 million less in funding than it was in

2010. It is simply not possible to meet the increasing demand for services and effectively provide transition services without additional funding. Increased funding should be reinvested from the billions currently spent to keep people with disabilities in costly Medicaid nursing homes and institutions and out of mainstream society.

Centers for Independent Living play a crucial role in the lives of people with disabilities, and work tirelessly to ensure that people with disabilities have a real choice in where and how they live, work, and participate in the community. Additionally, CILs are an excellent service and a bargain for America, keeping people engaged with their communities and saving taxpayer money. NCIL is dedicated to increasing the availability of the invaluable and extremely cost-effective services CILs provide, and they have submitted written testimony with a similar request. I strongly support NCIL's testimony.

Name: Donna Smith

Title: Program Director, Appalachian Independence Center

I am writing to support the National Council on Independent Living's request for Congress to reaffirm your commitment to the more than 57 million Americans disabilities by increasing funding in the HHS appropriations for Centers for Independent Living (CILs). I am asking that you increase funding by $200 million, for a total of $301 million for the Independent Living line item in FY 2017.

CILs are cross-disability, non-residential, community-based, nonprofit organizations that are designed and operated by individuals with disabilities. CILs are unique in that they are directly governed and staffed by people with all types of disabilities, including people with mental, physical, sensory, cognitive, and developmental disabilities. Each of the 365 federally funded centers provides five core services: information and referral, individual and systems advocacy, peer support, independent living skills training, and transition services, which were added with the passage of the Workforce Innovation and Opportunity Act (WIOA). From 2012-2014, CILs provided the core services to nearly 5 million people with disabilities, and provided additional services such as housing assistance, transportation, personal care attendants, and employment services to hundreds of thousands of individuals. During this same period, prior to transition being added as a core service, CILs transitioned 13,030 people with disabilities from nursing homes and other institutions into the community.

Transition services were added as a fifth core service with the 2014 reauthorization of the Rehabilitation Act within the Workforce Innovation and Opportunity Act. Transition services include the transition of individuals with significant disabilities from nursing homes and other institutions to home and community-based residences with appropriate supports and services, assistance to individuals with significant disabilities at risk of entering institutions to remain in the community, and the transition of youth with significant disabilities to postsecondary life. This core service is vital to achieving full participation for people with disabilities.

Every day, CILs are fighting to ensure that people with disabilities gain and maintain control over our own lives. We know that this cannot occur when people reside in institutional settings. Opponents of deinstitutionalization say that allowing people with disabilities to live in the community will result in harm. We know that the 13,030 people with disabilities who CILs successfully transitioned out of nursing homes and institutions from 2012-2014 prove otherwise. Additionally, when services are delivered in an individual's home, the result is a tremendous cost savings to Medicaid, Medicare, and states. Community-based services enable people with disabilities to become less reliant on long-term government supports, and they are significantly less expensive than nursing home placements. We are grateful that Congress demonstrated their understanding and support for community-based services when WIOA was passed and transition was added as a fifth core service.

Since transition services were added as a core service, the need for funding is critical. Moreover, CILs need additional funding to restore the devastating cuts to the Independent Living program, make up for inflation costs, and address the increased demand for independent living services. In

2016, the Independent Living Program is receiving $2.5 million less in funding than it was in 2010. It is simply not possible to meet the increasing demand for services and effectively provide transition services without additional funding. Increased funding should be reinvested from the billions currently spent to keep people with disabilities in costly Medicaid nursing homes and institutions and out of mainstream society.

Centers for Independent Living play a crucial role in the lives of people with disabilities, and work tirelessly to ensure that people with disabilities have a real choice in where and how they live, work, and participate in the community. Additionally, CILs are an excellent service and a bargain for America, keeping people engaged with their communities and saving taxpayer money. NCIL is dedicated to increasing the availability of the invaluable and extremely cost-effective services CILs provide, and they have submitted written testimony with a similar request. I strongly support NCIL's testimony.

Sincerely,
Donna Smith

Memphis Center For Independent Living
1633 Madison Avenue
Memphis, TN 38104
(901)726-6404
www.mcil.org

Diane T. (Sandi) Klink
Executive Director
Memphis Center for Independent Living

I am writing to support the National Council on Independent Living's request for Congress to reaffirm your commitment to the more than 57 million Americans disabilities by increasing funding in the HHS appropriations for Centers for Independent Living (CILs). I am asking that you increase funding by $200 million, for a total of $301 million for the Independent Living line item in FY 2017.

CILs are cross-disability, non-residential, community-based, nonprofit organizations that are designed and operated by individuals with disabilities. CILs are unique in that they are directly governed and staffed by people with all types of disabilities, including people with mental, physical, sensory, cognitive, and developmental disabilities. Each of the 365 federally funded centers provides five core services: information and referral, individual and systems advocacy, peer support, independent living skills training, and transition services, which were added with the passage of the Workforce Innovation and Opportunity Act (WIOA). From 2012-2014, CILs provided the core services to nearly 5 million people with disabilities, and provided additional services such as housing assistance, transportation, personal care attendants, and employment services to hundreds of thousands of individuals. During this same period, prior to transition being added as a core service, CILs transitioned 13,030 people with disabilities from nursing homes and other institutions into the community.

Transition services were added as a fifth core service with the 2014 reauthorization of the Rehabilitation Act within the Workforce Innovation and Opportunity Act. Transition services include the transition of individuals with significant disabilities from nursing homes and other institutions to home and community-based residences with appropriate supports and services, assistance to individuals with significant disabilities at risk of entering institutions to remain in the community, and the transition of youth with significant disabilities to postsecondary life. This core service is vital to achieving full participation for people with disabilities.

Every day, CILs are fighting to ensure that people with disabilities gain and maintain control over our own lives. We know that this cannot occur when people reside in institutional settings. Opponents of

deinstitutionalization say that allowing people with disabilities to live in the community will result in harm. We know that the 13,030 people with disabilities who CILs successfully transitioned out of nursing homes and institutions from 2012-2014 prove otherwise. Additionally, when services are delivered in an individual's home, the result is a tremendous cost savings to Medicaid, Medicare, and states. Community-based services enable people with disabilities to become less reliant on long-term government supports, and they are significantly less expensive than nursing home placements. We are grateful that Congress demonstrated their understanding and support for community-based services when WIOA was passed and transition was added as a fifth core service.

Since transition services were added as a core service, the need for funding is critical. Moreover, CILs need additional funding to restore the devastating cuts to the Independent Living program, make up for inflation costs, and address the increased demand for independent living services. In 2016, the Independent Living Program is receiving $2.5 million less in funding than it was in 2010. It is simply not possible to meet the increasing demand for services and effectively provide transition services without additional funding. Increased funding should be reinvested from the billions currently spent to keep people with disabilities in costly Medicaid nursing homes and institutions and out of mainstream society. As an example of these losses in funding MCIL experienced what many are calling the ARRA cliff and a loss of $76,000 forcing the end of unserved outreach, senior low vision computer classes and layoff of 2.5 staff. Providing additional services with fewer people cannot be reasonable expected. A loss of this magnitude on top of requiring coverage of new services has put our Center and many others across the country in untenable situations.

Centers for Independent Living play a crucial role in the lives of people with disabilities, and work tirelessly to ensure that people with disabilities have a real choice in where and how they live, work, and participate in the community. Additionally, CILs are an excellent service and a bargain for America, keeping people engaged with their communities and saving taxpayer money. NCIL is dedicated to increasing the availability of the invaluable and extremely cost-effective services CILs provide, and they have submitted written testimony with a similar request. I strongly support NCIL's testimony.

325 John Knox Rd., Bldg C, Ste 132 · Tallahassee, FL 32303
Ph: (850) 575-6004 · Fax: (850) 575-6093 · www.floridacils.org

Florida Association of
Centers for Independent Living

House Committee on Appropriations Subcommittee on
Labor, Health and Human Services,
Education, and Related Agencies

April 11, 2016

Dear Committee Members:

On behalf of 15 Centers for Independent Living serving the State of Florida, I am writing to support the National Council on Independent Living's request for Congress to reaffirm your commitment to the more than 57 million Americans disabilities by increasing funding in the HHS appropriations for Centers for Independent Living (CILs). I am asking that you increase funding by $200 million, for a total of $301 million for the Independent Living line item in FY 2017. Adequate funding is critical for assisting people with all types of disabilities in this state.

CILs are cross-disability, non-residential, community-based, nonprofit organizations that are designed and operated by individuals with disabilities. CILs are unique in that they are directly governed and staffed by people with all types of disabilities, including people with mental, physical, sensory, cognitive, and developmental disabilities. Each of the 365 federally funded centers provides five core services: information and referral, individual and systems advocacy, peer support, independent living skills training, and transition services, which were added with the passage of the Workforce Innovation and Opportunity Act (WIOA). From 2012-2014, CILs provided the core services to nearly 5 million people with disabilities, and provided additional services such as housing assistance, transportation, personal care attendants, and employment services to hundreds of thousands of individuals. During this same period, prior to transition being added as a core service, CILs transitioned 13,030 people with disabilities from nursing homes and other institutions into the community.

Transition services were added as a fifth core service with the 2014 reauthorization of the Rehabilitation Act within the Workforce Innovation and Opportunity Act. Transition services include the transition of individuals with significant disabilities from nursing homes and other institutions to home and community-based residences with appropriate supports and services, assistance to individuals with significant disabilities at risk of entering institutions to remain in the community, and the transition of youth with significant disabilities to postsecondary life. This core service is vital to achieving full participation for people with disabilities.

Every day, CILs are fighting to ensure that people with disabilities gain and maintain control over their own lives. We know that this cannot occur when people reside in institutional settings. Opponents of deinstitutionalization say that allowing people with disabilities to live in the community will result in harm. We know that the 13,030 people with disabilities who CILs

successfully transitioned out of nursing homes and institutions from 2012-2014 prove otherwise. Additionally, when services are delivered in an individual's home, the result is a tremendous cost savings to Medicaid, Medicare, and states. Community-based services enable people with disabilities to become less reliant on long-term government supports, and they are significantly less expensive than nursing home placements. We are grateful that Congress demonstrated their understanding and support for community-based services when WIOA was passed and transition was added as a fifth core service.

Since transition services were added as a core service, the need for funding is critical. Moreover, CILs need additional funding to restore the devastating cuts to the Independent Living program, make up for inflation costs, and address the increased demand for independent living services. In 2016, the Independent Living Program is receiving $2.5 million less in funding than it was in 2010. It simply is not possible to meet the increasing demand for services and effectively provide transition services without additional funding. Increased funding should be reinvested from the billions currently spent to keep people with disabilities in costly Medicaid nursing homes and institutions and out of mainstream society.

Centers for Independent Living play a crucial role in the lives of people with disabilities, and work tirelessly to ensure that people with disabilities have a real choice in where and how they live, work, and participate in the community. Additionally, CILs are an excellent service and a bargain for America, keeping people engaged with their communities and saving taxpayer money. NCIL is dedicated to increasing the availability of the invaluable and extremely cost-effective services CILs provide, and they have submitted written testimony with a similar request. Florida's Centers for Independent Living strongly support NCIL's testimony.

Sincerely,

Linda A. Keen

Linda A. Keen MSN, JD
Executive Director
Florida Association for Independent Living, Inc.
linda@floridacils.org

Northwestern Illinois Center for Independent Living
412 Locust St.
Sterling, IL 61081
815-625-7860
Website at www.nicil.org

Michele Miller
Executive Director
Northwestern Illinois Center for Independent Living (NICIL)

I am writing to support the National Council on Independent Living's request for Congress to reaffirm your commitment to the more than 57 million Americans disabilities by increasing funding in the HHS appropriations for Centers for Independent Living (CILs). I am asking that you increase funding by $200 million, for a total of $301 million for the Independent Living line item in FY 2017.

If you aren't familiar with CILs then please note the important role we play in our communities throughout the US. We support independent living through services in our communities. We are first hand, hands on, living examples of people with disabilities as 51% or more of our staff, volunteers, and Board of Directors are people with disabilities. We live the challenges of negotiating a barrier laden, negative attitude, and ever changing world. Yet every day we come to NICIL to serve our consumers; people just like us, working to live independently in a perplexing environment. We succeed because we serve our consumers and our communities.

CILs are cross-disability, non-residential, community-based, nonprofit organizations that are designed and operated by individuals with disabilities. CILs are unique in that they are directly governed and staffed by people with all types of disabilities, including people with mental, physical, sensory, cognitive, and developmental disabilities. Each of the 365 federally funded centers provides five core services: information and referral, individual and systems advocacy, peer support, independent living skills training, and transition services, which were added with the passage of the Workforce Innovation and Opportunity Act (WIOA). From 2012-2014, CILs provided the core services to nearly 5 million people with disabilities, and provided additional services such as housing assistance, transportation, personal care attendants, and employment services to hundreds of thousands of individuals. During this same period, prior to transition being added as a core service, CILs transitioned 13,030 people with disabilities from nursing homes and other institutions into the community.

Transition services were added as a fifth core service with the 2014 reauthorization of the Rehabilitation Act within the Workforce Innovation and Opportunity Act. Transition services include the transition of individuals with significant disabilities from nursing homes and other institutions to home and community-based residences with appropriate supports and services, assistance to individuals with significant disabilities at risk of entering institutions to remain in the community, and the transition of youth

with significant disabilities to postsecondary life. This core service is vital to achieving full participation for people with disabilities.

Every day, CILs are fighting to ensure that people with disabilities gain and maintain control over our own lives. We know that this cannot occur when people reside in institutional settings. Opponents of deinstitutionalization say that allowing people with disabilities to live in the community will result in harm. We know that the 13,030 people with disabilities who CILs successfully transitioned out of nursing homes and institutions from 2012-2014 prove otherwise. Additionally, when services are delivered in an individual's home, the result is a tremendous cost savings to Medicaid, Medicare, and states. Community-based services enable people with disabilities to become less reliant on long-term government supports, and they are significantly less expensive than nursing home placements. We are grateful that Congress demonstrated their understanding and support for community-based services when WIOA was passed and transition was added as a fifth core service.

Since transition services were added as a core service, the need for funding is critical. Moreover, CILs need additional funding to restore the devastating cuts to the Independent Living program, make up for inflation costs, and address the increased demand for independent living services. In 2016, the Independent Living Program is receiving $2.5 million less in funding than it was in 2010. It is simply not possible to meet the increasing demand for services and effectively provide transition services without additional funding. Increased funding should be reinvested from the billions currently spent to keep people with disabilities in costly Medicaid nursing homes and institutions and out of mainstream society.

Centers for Independent Living play a crucial role in the lives of people with disabilities, and work tirelessly to ensure that people with disabilities have a real choice in where and how they live, work, and participate in the community. Additionally, CILs are an excellent service and a bargain for America, keeping people engaged with their communities and saving taxpayer money. NCIL is dedicated to increasing the availability of the invaluable and extremely cost-effective services CILs provide, and they have submitted written testimony with a similar request. I strongly support NCIL's testimony.

Kristin L. Vehrs, Executive Director
Association of Zoos and Aquariums
Testimony – House Subcommittee on Labor, Health and Human Services, Education and Related Agencies

Thank you Chairman Cole and Ranking Member DeLauro for allowing me to submit testimony on behalf of the nation's 217 AZA-accredited zoos and aquariums. Specifically, I want to express my support for the inclusion of $38.6 million for the Institute of Museum and Library Services' (IMLS) Office of Museum Services in the FY2017 Labor, Health and Human Services, Education, and Related Agencies appropriations bill.

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

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

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

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

As museums, zoos and aquariums share the same mission of preserving the world's great treasures, educating the public about them, and contributing to the nation's economic and cultural vitality. Therefore, I strongly encourage you to include $38.6 million for the Institute of Museum and Library Services' Office of Museum Services in the FY2017 Labor, Health and Human Services, Education, and Related Agencies appropriations bill.

Thank you for your consideration of our comments.

SCRS-IL | Southern California Resource Services for Independent Living

Arturo Nevarez

Program Manager for Accessibility and Systematic Change

Southern CA Resource Services for Independent Living

I am writing to support the National Council on Independent Living's request for Congress to reaffirm your commitment to the more than 57 million Americans disabilities by increasing funding in the HHS appropriations for Centers for Independent Living (CILs). I am asking that you increase funding by $200 million, for a total of $301 million for the Independent Living line item in FY 2017.

CILs are cross-disability, non-residential, community-based, nonprofit organizations that are designed and operated by individuals with disabilities. CILs are unique in that they are directly governed and staffed by people with all types of disabilities, including people with mental, physical, sensory, cognitive, and developmental disabilities. Each of the 365 federally funded centers provides five core services: information and referral, individual and systems advocacy, peer support, independent living skills training, and transition services, which were added with the passage of the Workforce Innovation and Opportunity Act (WIOA). From 2012-2014, CILs provided the core services to nearly 5 million people with disabilities, and provided additional

services such as housing assistance, transportation, personal care attendants, and employment services to hundreds of thousands of individuals. During this same period, prior to transition being added as a core service, CILs transitioned 13,030 people with disabilities from nursing homes and other institutions into the community.

Transition services were added as a fifth core service with the 2014 reauthorization of the Rehabilitation Act within the Workforce Innovation and Opportunity Act. Transition services include the transition of individuals with significant disabilities from nursing homes and other institutions to home and community-based residences with appropriate supports and services, assistance to individuals with significant disabilities at risk of entering institutions to remain in the community, and the transition of youth with significant disabilities to postsecondary life. This core service is vital to achieving full participation for people with disabilities.

Every day, CILs are fighting to ensure that people with disabilities gain and maintain control over our own lives. We know that this cannot occur when people reside in institutional settings. Opponents of deinstitutionalization say that allowing people with disabilities to live in the community will result in harm. We know that the 13,030 people with disabilities who CILs successfully transitioned out of nursing homes and institutions from 2012-2014 prove otherwise. Additionally, when services are delivered in an individual's home, the result is a tremendous cost savings to Medicaid, Medicare, and states. Community-based services enable people with disabilities to become less reliant on long-term government supports, and they are significantly less expensive than nursing home placements. We are grateful that Congress demonstrated their

understanding and support for community-based services when WIOA was passed and transition was added as a fifth core service.

Since transition services were added as a core service, the need for funding is critical. Moreover, CILs need additional funding to restore the devastating cuts to the Independent Living program, make up for inflation costs, and address the increased demand for independent living services. In 2016, the Independent Living Program is receiving $2.5 million less in funding than it was in 2010. It is simply not possible to meet the increasing demand for services and effectively provide transition services without additional funding. Increased funding should be reinvested from the billions currently spent to keep people with disabilities in costly Medicaid nursing homes and institutions and out of mainstream society.

Centers for Independent Living play a crucial role in the lives of people with disabilities, and work tirelessly to ensure that people with disabilities have a real choice in where and how they live, work, and participate in the community. Additionally, CILs are an excellent service and a bargain for America, keeping people engaged with their communities and saving taxpayer money. NCIL is dedicated to increasing the availability of the invaluable and extremely cost-effective services CILs provide, and they have submitted written testimony with a similar request. I strongly support NCIL's testimony.

Kelly Buckland
Executive Director
National Council on Independent Living (NCIL)
Prepared for the House Appropriations Subcommittee on Labor, Health and Human Services, Education, and Related Agencies

Dear Chairman Cole, Ranking Member DeLauro, Vice Chair Womack, and Members of the Subcommittee,

My name is Kelly Buckland, and I am the Executive Director of the National Council on Independent Living (NCIL). I am writing to you on behalf of the nation's Centers for Independent Living (CILs). I would like to start by thanking you for your commitment to enabling people with disabilities to participate fully in their communities by investing in the Independent Living Program. I write today to ask that you reaffirm your commitment to the over 57 million Americans with disabilities by increasing funding for CILs in the U.S. Department of Health and Human Services appropriations by $200 million, for a total of $301 million for the Independent Living line item in FY 2017.

NCIL is dedicated to increasing the availability of the invaluable and extremely cost-effective services CILs provide. NCIL is the oldest cross-disability, national grassroots organization run by and for people with disabilities. NCIL's membership includes people with disabilities, Centers for Independent Living, Statewide Independent living Councils, and other disability rights organizations. NCIL advances independent living and the rights of people with disabilities, and we envision a world in which people with disabilities are valued equally and participate fully.

Centers for Independent Living are non-residential, community-based, non-profit organizations that are designed and operated by individuals with disabilities and provide five core services: advocacy, information and referral, peer support, independent living skills training and transition services that facilitate the transition of individuals with significant disabilities from nursing homes and other institutions to home and community-based residences with appropriate supports and services. Also included are assistance to individuals with significant disabilities who are at risk of entering institutions so that the individuals may remain in the community, and the transition of youth with significant disabilities to postsecondary life.

CILs are unique in that they operate according to a strict philosophy of consumer control, in which people with any type of disability, including people with mental, physical, sensory, cognitive, and developmental disabilities, of any age, directly govern and staff the Center. Each of the 365 federally funded Centers are unique because they are run by people with disabilities and reflect the best interest of each community individually.

Centers for Independent Living address discrimination and barriers that exist in society through direct advocacy. These barriers are sometimes architectural, but more often reflect attitudes and prejudices that have been reinforced for generations. They have deterred people with disabilities from working, leaving many in poverty and unjustly detained in institutions. As my own life experience has proven, with increased opportunities, individuals with disabilities can claim their civil rights and participate in their communities in ways their non-disabled counterparts often take for granted.

NCIL estimates that to meet the current demand- including the addition of a fifth core service as authorized by WIOA- and overcome years of devastating funding cuts, appropriations for the IL Program will need to increase by $200 million. In FY 2010 funding for the IL Program was $103,716,000, and in FY 2016 funding for the IL Program is $101,183,000. That equals a loss of $2.5 million, not including adjusting for inflation. Increased funding should be reinvested from the billions currently spent to keep people with disabilities in costly Medicaid nursing homes and institutions and out of mainstream of society.

According to data collected by the Rehabilitation Services Administration, during Fiscal Years 2012-2014, Centers for Independent Living:

- Attracted over $2.26 Billion through private, state, local, and other sources;
- Moved 13,030 people out of nursing homes and institutions, saving states and the Federal government over $500 million, not to mention improving people's quality of life, and;
- Provided the four core services, including: advocacy to 233,230 consumers, information and referral to 4,189,922 consumers, peer support to 172,287 consumers, and independent living skills training to 274,991 consumers.

In that same period, CILs provided other services to hundreds of thousands of individuals with disabilities in their respective communities that included:

- Services to 35,137 youth with disabilities;
- Assistance to 145,937 people in securing accessible, affordable, and integrated housing;
- Transportation services to 103,175 people with disabilities;
- Personal assistance services to 184,240 people with disabilities;
- Vocational and employment services to 96,492 people with disabilities; and
- Assistance with Assistive Technology for 171,441 people with disabilities.

Beyond the direct services they provide, CILs seek ways to broadly change traditional service delivery in their communities and throughout the nation, including reform of the long term care system. For over 40 years, CILs have sought community based programs to assist people with all types of disabilities, across the lifespan, to remain in or return to their family and friends, in their homes and communities. When such services are delivered in an individual's home, rather than a costly nursing facility or other institution, the result is tremendous cost savings to Medicaid, Medicare and states, while enabling people with disabilities to become more independent, financially self-sufficient, and less reliant on long term government supports. And research has found that community-based services are significantly less expensive than nursing home placements.

In 2015 alone, CILs have had major successes in increasing access and equality for people with disabilities. The DIAL Center for Independent Living in Clifton, New Jersey joined a local wheelchair user in efforts to work with the city of Montclair, and those efforts will result in accessible parking spaces outside schools, parks, and other public parking areas, as well as the hiring of an ADA Coordinator for the city. The Montana Independent living Project collaborated on a snow ordinance policy for the city of Helena that requires sidewalks, ADA ramps, corners, bulb-outs, and driveway and alley aprons used for pedestrian travel to be cleared within 24 hours, with enforcement and penalties for non-compliance. Access Living in Chicago, Illinois conducted phone-based fair housing tests and used the results to draw attention to the issue of discrimination against home seekers who are Deaf or hard of hearing. And the

Disabled Resource Services CIL (DRS) in Fort Collins and Loveland, Colorado conducted its first Women's Empowerment Group, which has led to ongoing efforts by DRS staff to create an empirical research design model that can be used in future groups to quantitively measure the concept of "empowerment," an area of study in which little research exists.

Additionally, CILs have been extremely effective in helping people remain in or transition back into the community. The Whole Person's Money Follows the Person program completed 32 consumer transitions from institutions to apartments/homes in the Kansas City, Missouri metro area. Tri-County Patriots for Independent Living in Washington, Pennsylvania transitioned 54 people from nursing homes and other institutions into their own homes, saving the state and federal government $2,268,000. The Houston Center for Independent Living in Texas transitioned 186 nursing home residents into community-based living, saving the State of Texas and the federal government approximately $8,779,200. And the Center for Disability Rights in Rochester, New York was instrumental in achieving introduction of the Disability Integration Act by Senator Schumer, which has the potential to provide access to community services and supports to people with disabilities all across the country.

As previously mentioned, the Workforce Innovation and Opportunity Act created a fifth core service for Centers: transition. NCIL strongly supported the addition of this fifth core service, but additional funding is sorely needed to effectively carry it out. Funding these transition services will be critical to promoting effective employment outcomes, successful nursing home transition, and increased community participation for transitioning students. Current funding levels barely sustain day-to-day operations. CILs struggle to meet the demands of the community and provide leadership and common sense solutions. Without increased funds our vision to achieve full integration of people with disabilities in society will be undercut and taxpayers will continue to pay for costly Medicaid nursing homes and bear the economic impact of negative employment outcomes and continued dependence on programs that disincentive work and community involvement. CILs are an excellent service and a bargain for America. They keep people active and engaged in their communities, and they save taxpayer money.

Thank you for the opportunity to provide testimony. We welcome any questions you may have. We also welcome each of you to visit your local Center for Independent Living so you can see first-hand their contributions to your Congressional Districts. We look forward to working with you to ensure that Americans with disabilities have the opportunity become active members of society.

Name Michael Warburton

Title: Transition Coordinator, Money Follows the Person Rebalancing Project

Institutional Affiliation: Independence Northwest

I am writing to support the National Council on Independent Living's request for Congress to reaffirm your commitment to the more than 57 million Americans disabilities by increasing funding in the HHS appropriations for Centers for Independent Living (CILs). I am asking that you increase funding by $200 million, for a total of $301 million for the Independent Living line item in FY 2017.

CILs are cross-disability, non-residential, community-based, nonprofit organizations that are designed and operated by individuals with disabilities. CILs are unique in that they are directly governed and staffed by people with all types of disabilities, including people with mental, physical, sensory, cognitive, and developmental disabilities. Each of the 365 federally funded centers provides five core services: information and referral, individual and systems advocacy, peer support, independent living skills training, and transition services, which were added with the passage of the Workforce Innovation and Opportunity Act (WIOA). From 2012-2014, CILs provided the core services to nearly 5 million people with disabilities, and provided additional services such as housing assistance, transportation, personal care attendants, and employment services to hundreds of thousands of individuals. During this same period, prior to transition being added as a core service, CILs transitioned 13,030 people with disabilities from nursing homes and other institutions into the community.

Transition services were added as a fifth core service with the 2014 reauthorization of the Rehabilitation Act within the Workforce Innovation and Opportunity Act. Transition services include the transition of individuals with significant disabilities from nursing homes and other institutions to home and community-based residences with appropriate supports and services, assistance to individuals with significant disabilities at risk of entering institutions to remain in the community, and the transition of youth with significant disabilities to postsecondary life. This core service is vital to achieving full participation for people with disabilities.

Every day, CILs are fighting to ensure that people with disabilities gain and maintain control over our own lives. We know that this cannot occur when people reside in institutional settings. Opponents of deinstitutionalization say that allowing people with disabilities to live in the community will result in harm. We know that the 13,030 people with disabilities who CILs successfully transitioned out of nursing homes and institutions from 2012-2014 prove otherwise. Additionally, when services are delivered in an individual's home, the result is a tremendous cost savings to Medicaid, Medicare, and states. Community-based services enable people with disabilities to become less reliant on long-term government supports, and they are significantly less expensive than nursing home placements. We are grateful that Congress demonstrated their understanding and support for community-based services when WIOA was passed and transition was added as a fifth core service.

Since transition services were added as a core service, the need for funding is critical. Moreover, CILs need additional funding to restore the devastating cuts to the Independent Living program, make up for inflation costs, and address the increased demand for independent living services. In

2016, the Independent Living Program is receiving $2.5 million less in funding than it was in 2010. It is simply not possible to meet the increasing demand for services and effectively provide transition services without additional funding. Increased funding should be reinvested from the billions currently spent to keep people with disabilities in costly Medicaid nursing homes and institutions and out of mainstream society.

Centers for Independent Living play a crucial role in the lives of people with disabilities, and work tirelessly to ensure that people with disabilities have a real choice in where and how they live, work, and participate in the community. Additionally, CILs are an excellent service and a bargain for America, keeping people engaged with their communities and saving taxpayer money. NCIL is dedicated to increasing the availability of the invaluable and extremely cost-effective services CILs provide, and they have submitted written testimony with a similar request. I strongly support NCIL's testimony.

Name Michael Warburton

Title: Transition Coordinator, Money Follows the Person Rebalancing Project

Institutional Affiliation: Independence Northwest

I am writing to support the National Council on Independent Living's request for Congress to reaffirm your commitment to the more than 57 million Americans disabilities by increasing funding in the HHS appropriations for Centers for Independent Living (CILs). I am asking that you increase funding by $200 million, for a total of $301 million for the Independent Living line item in FY 2017.

CILs are cross-disability, non-residential, community-based, nonprofit organizations that are designed and operated by individuals with disabilities. CILs are unique in that they are directly governed and staffed by people with all types of disabilities, including people with mental, physical, sensory, cognitive, and developmental disabilities. Each of the 365 federally funded centers provides five core services: information and referral, individual and systems advocacy, peer support, independent living skills training, and transition services, which were added with the passage of the Workforce Innovation and Opportunity Act (WIOA). From 2012-2014, CILs provided the core services to nearly 5 million people with disabilities, and provided additional services such as housing assistance, transportation, personal care attendants, and employment services to hundreds of thousands of individuals. During this same period, prior to transition being added as a core service, CILs transitioned 13,030 people with disabilities from nursing homes and other institutions into the community.

Transition services were added as a fifth core service with the 2014 reauthorization of the Rehabilitation Act within the Workforce Innovation and Opportunity Act. Transition services include the transition of individuals with significant disabilities from nursing homes and other institutions to home and community-based residences with appropriate supports and services, assistance to individuals with significant disabilities at risk of entering institutions to remain in the community, and the transition of youth with significant disabilities to postsecondary life. This core service is vital to achieving full participation for people with disabilities.

Every day, CILs are fighting to ensure that people with disabilities gain and maintain control over our own lives. We know that this cannot occur when people reside in institutional settings. Opponents of deinstitutionalization say that allowing people with disabilities to live in the community will result in harm. We know that the 13,030 people with disabilities who CILs successfully transitioned out of nursing homes and institutions from 2012-2014 prove otherwise. Additionally, when services are delivered in an individual's home, the result is a tremendous cost savings to Medicaid, Medicare, and states. Community-based services enable people with disabilities to become less reliant on long-term government supports, and they are significantly less expensive than nursing home placements. We are grateful that Congress demonstrated their understanding and support for community-based services when WIOA was passed and transition was added as a fifth core service.

Since transition services were added as a core service, the need for funding is critical. Moreover, CILs need additional funding to restore the devastating cuts to the Independent Living program, make up for inflation costs, and address the increased demand for independent living services. In

2016, the Independent Living Program is receiving $2.5 million less in funding than it was in 2010. It is simply not possible to meet the increasing demand for services and effectively provide transition services without additional funding. Increased funding should be reinvested from the billions currently spent to keep people with disabilities in costly Medicaid nursing homes and institutions and out of mainstream society.

Centers for Independent Living play a crucial role in the lives of people with disabilities, and work tirelessly to ensure that people with disabilities have a real choice in where and how they live, work, and participate in the community. Additionally, CILs are an excellent service and a bargain for America, keeping people engaged with their communities and saving taxpayer money. NCIL is dedicated to increasing the availability of the invaluable and extremely cost-effective services CILs provide, and they have submitted written testimony with a similar request. I strongly support NCIL's testimony.

Academy of Nutrition and Dietetics

Testimony Prepared by the Academy of Nutrition and Dietetics for the United State House Committee on Labor, Health and Human Services, and Education, and Related Agencies addressed to the Department of Health and Human Services

April 15, 2015

The Academy of Nutrition and Dietetics (the "Academy") is part of a nationwide coalition, the Food is Medicine Coalition, of over 80 food and nutrition services providers, affiliates and their supporters across the country that provide food and nutrition services to people living with HIV/AIDS (PWH) and other chronic illnesses. The Academy, with 76,000 members throughout the nation, is the world's largest organization of food and nutrition professionals, committed to improving the nation's health through healthy and safe food choices. Collectively, the Food is Medicine Coalition is committed to increasing awareness of the essential role that food and nutrition services (FNS) play in successfully treating HIV/AIDS and to expanding access to this indispensable intervention for people living with other severe illnesses.

1.) Why Food and Nutrition Services (FNS) Matter for PWH

While adequate food and nutrition are basic to maintaining health for all persons, good nutrition is crucial for the management of HIV infection. Proper nutrition is needed to increase absorption of medication, reduce side effects, and maintain healthy body weight. Research has identified the virus as an independent risk factor for cardiovascular, liver and kidney disease, cancer, osteoporosis and stroke. Several HIV medications can cause nausea and vomiting and some can affect lab results that test lipids and kidney and liver function. These compounding health effects, caused by the virus and its medications, reinforce the important role a nutrient-rich diet plays in a patient's overall care plan. In addition, providing food and nutrition services can serve to facilitate access and engagement with medical care, especially among vulnerable populations.

The Food and Nutrition Services category within the Ryan White Program includes medical nutritional therapy (MNT) and food and nutrition services (FNS). MNT covers nutritional diagnostic, therapy, and counseling services focused on prevention, delay or management of diseases and conditions, and involves an in-depth assessment, periodic reassessment and intervention provided by a licensed, Registered Dietitian Nutritionist (RDN) outside of a primary care visit. The range of FNS provided through the Ryan White program complements the needs of PWH at any stage of their illness. For those who are most mobile, there are congregate meals, walk-in food pantries and voucher programs. For those whose disease has progressed, home-delivered meals and home-delivered grocery bags complement their medical treatment.

Since 2006, HRSA has included MNT and FNS, provided under the guidance of RDNs, as a clinically effective **core medical service** in the Ryan White Program. These services play a critical role in ensuring that PWH enter and continue in primary medical care, adhere to their medications, and ultimately achieve viral suppression.

2.) FNS as a Care Completion Service Unique to Ryan White

Social and economic interventions, most often in the form of care completion service like food and nutrition services, are fundamental to making health care work for PWH. Support services for PWH are not covered in any comprehensive way by Medicaid or other public insurance initiatives that have been expanded by the Affordable Care Act. As the HIV epidemic in the United States increasingly impacts low-income individuals, support services help stabilize individuals living with or at risk of HIV. When needs are met, and life's emergencies are held at bay, PWH are poised to remain connected to care and treatment.

3.) Access to FNS and the Triple Aim

Access to appropriate food and nutrition services (FNS) are increasingly recognized as key to accomplishing the triple aim of national healthcare reform for PWH.

Better Health Outcomes

When clients get effective FNS and become food secure, they then keep scheduled primary care visits, score higher on health functioning, are at lower risk for inpatient hospital stays and are more likely to take their medicines[i]. Studies show both the health benefits of access to MNT and/or nutrition counseling for people with HIV infections[ii] and the resulting decreases in their healthcare costs. Compare these outcomes to PWH who are food insecure, who have:

- Lower CD4 counts & lower likelihoods of having undetectable viral loads[iii]
- More ER visits[iv] & increased morbidity and mortality[v]
- More missed primary care appointments & reduced use of antiretroviral therapy[vi].

Lower Healthcare Costs

Millions of dollars in healthcare expenditures are saved through the provision of FNS to PWH. A recent study comparing participants in a medically-tailored FNS program vs. a control group within a local managed care organization found that average monthly healthcare costs for PWH fell 80% in first three months after receiving FNS[vii]. If hospitalized, nourished clients' costs were 30% lower, their hospital length of stay was cut by 37% and they were 20% more likely to be able to be discharged to their homes rather than a more expensive institution[viii]. Furthermore, FNS are a very inexpensive intervention. For each day in a hospital saved, you can feed a person a medically-tailored diet for half a year.

Improved Patient Satisfaction

Studies show nutrition counseling improves quality of life[ix]. Members overwhelmingly report that our services help them live more independently, eat more nutritiously and manage their medical treatment more effectively.

4.) FNS and the National HIV/AIDS Strategy (NHAS)

Access to FNS for PWH is fundamental to fulfilling the goals of the NHAS.

- **NHAS Goal: Reducing new HIV infections:** PWH who are food insecure are less likely to have undetectable viral loads in a statistically significant way. Undetectable viral loads prevent transmission 96% of the time[x], thus, FNS is key to prevention[xi].
- **NHAS Goal: Increasing access to care and improving health outcomes for people living with HIV:** PWH who receive effective FNS are more likely to keep scheduled primary care

visits, score higher on health functioning, are at lower risk for inpatient hospital stays and are more likely to take their medicines[xii].

- **NHAS Goal: Reducing HIV-related disparities and health inequities:** By providing FNS to PWH who are in need largely because of poverty, we improve health outcomes, thereby reducing health disparities[xiii].
- **NHAS Goal: Achieving a more coordinated national response to the HIV epidemic:** There remains a tremendous variation by state in coverage of food and nutrition services both inside and outside of Ryan White, making support for Ryan White HIV Program all the more needed. Ultimately, if we are going to achieve a more coordinated national response to the HIV epidemic and our quest to reduce healthcare spending nationwide, FNS must be included in all healthcare reform efforts, including Ryan White and the ACA.

Conclusion

We are deeply aware of the difficult decisions that face the members of the Committee in the current fiscal environment. Yet, research shows that investment in FNS, with the great return in prevention and retention in HIV care, are vital to lowering the number of new infections in the domestic HIV epidemic and ultimately reducing healthcare costs and preserving healthcare resources for the future. A client's diet can literally have life and death consequences. When people are severely ill, good nutrition is one of the first things to deteriorate, making recovery and stabilization that much harder, if not impossible. Early and reliable access to medically-appropriate FNS helps PWH live healthy and productive lives, produces better overall health outcomes and reduces health care costs.

Along with our colleagues, we appreciate the opportunity to offer this testimony regarding the FY 2017 Appropriations process. We are also pleased to offer our assistance and expertise, including information from our Research Library.

Respectfully submitted,

Mary Pat Raimondi, MS, RD
Vice President, Strategic Policy and Partnerships
1120 Connecticut Ave, NW Suite 460
Washington, DC 20036
mraimondi@eatright.org
312.899.1731

---

[i] Aidala A, Yomogida M, Vardy Y & the Food & Nutrition Study Team. Food and Nutrition Services, HIV Medical Care, and Health Outcomes. New York State Department of Health: Resources for Ending the Epidemic, 2014. Available at https://www.health.ny.gov/diseases/aids/ending_the_epidemic/docs/key_resources/housing_and_supportive_services/chain_factsheet3.pdf

[ii] Academy of Nutrition and Dietetics (formerly American Dietetic Association). HIV/AIDS Nutrition Evidence Analysis Project at http://www.adaevidencelibrary.com/conclusion.cfm?conclusion_statement_id=250707 Accessed 29 July 2012.

[iii] Aidala A., Yomogida M., and the HIV Food & Nutrition Study Team (2011);

Singe AW,Weiser SD, McCoy, SI. Does Food Insecurity Undermine Adherence to Antiretroviral Therapy? A Systematic Review. AIDS Behav (2015) 19:1510–1526.

[iv] Ibid.

[v] Anema A, Chan K, Yip B, Weiser S, Montaner JSG, Hogg RS. Impact of food insecurity on survival among HIV-positive injection drug users receiving antiretroviral therapy in a Canadian cohort. 141st APHA Annual Meeting, Nov. 2-6, 2013. Boston, MA. Abstract #: 290277

[vi] Aidala A., Yomogida M., and the HIV Food & Nutrition Study Team (2011).

[vii] Gurvey J, Rand K, Daugherty S, Dinger C, Schmeling J, Laverty N. Examining Health Care Costs Among MANNA Clients and a Comparison Group. J Prim Care Community Health. (2013) 4:311-317

[viii]Ibid.

[ix] Rabeneck L, Palmer A, Knowles JB, Seidehamel RJ, Harris CL, Merkel KL, Risser JMH, Akrabawi SS. A randomized controlled trial evaluating nutrition counseling with or without oral supplementation in malnourished HIV-infected patients. J Am Diet Assoc. (1998) 98: 434-438;Schwenk A, Steuck H, Kremer G. Oral supplements as adjunctive treatment to nutritional counseling in malnourished HIV-infected patients: randomized controlled trial. Clinical Nutrition (1999) 18(6): 371-374.

[x] M. S. Cohen *et al.*, Prevention of HIV-1 Infection with Early Antiretroviral Therapy. N. Engl. J. Med.(2011) 365, 493-505 . HPTN 052

[xi] Palar K, Laraia B, Tsai A, Weiser SD Food insecurity is associated with sexually transmitted infections and HIV serostatus among low income adults in the National Health and Nutrition Examination Survey (NHANES) (1999-2010). Presented at the American Public Health Association 141st Annual Meeting, Boston, MA, November 5, 2013.

[xii] Aidala A, Yomogida M, Vardy Y & the Food & Nutrition Study Team. Food and Nutrition Services, HIV Medical Care, and Health Outcomes. New York State Department of Health: Resources for Ending the Epidemic, 2014. Available at

xiii Weiser SD, Frongillo EA, Ragland K, Hogg RS, Riley ED, Bangsberg DR. Food insecurity is associated with incomplete HIV RNA suppression among homeless and marginally housed HIV-infected individuals in San Francisco. J Gen Intern Med. (2009) 24(1):14-20.

BRAIN INJURY ASSOCIATION OF AMERICA

1608 Spring Hill Road | Suite 110 | Vienna, VA 22182
Phone: (703) 761-0750 | Fax: (703) 761-0755
www.biausa.org

THE VOICE OF BRAIN INJURY

Testimony of the Brain Injury Association of America

Prepared for the Subcommittee on Labor, Health and Human Services, Education and Related Agencies

On Administration for Community Living, CDC, NIDILRR – Administration for Community Living

April 15, 2016

Chairman Cole and Ranking Member DeLauro, thank you for the opportunity to submit this written testimony with regard to the Fiscal Year (FY) 2017 Labor-HHS-Education appropriations bill. This testimony is on behalf of the Brain Injury Association of America (BIAA), our network of state affiliates, and hundreds of local chapters and support groups from across the country.

In the civilian population alone every year, more than 2.5 million people sustain brain injuries from falls, car crashes, assaults, and contact sports. Males are more likely than females to sustain brain injuries. Children, teens, and seniors are at greatest risk. Currently, more than 5 million Americans live with a TBI-related disability.

Increasing numbers of service members returning from the conflicts in Iraq and Afghanistan with TBI and their families are seeking resources for information to better understand TBI and to obtain vital support services to facilitate successful reintegration into their communities.

Administration for Community Living - The TBI Act authorizes the Administration for Community Living (ACL) in the Department of Health and Human Services (HHS) to award grants to (1) states, American Indian Consortia and territories to improve access to service delivery and to (2) state Protection and Advocacy (P&A) Systems to expand advocacy services to include individuals with traumatic brain injury. For the past seventeen 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 FY2009, the number of state grant awards was reduced to 15, later adding three more states, in order to increase each monetary award from $118,000 to $250,000. This means that many states that had participated in the program in past years have now been forced to close down their operations, leaving many unable to access brain injury care.

Increased funding of the program will provide resources necessary to sustain the grants for the 20 states currently receiving funding and to ensure funding for additional states. Steady increases over five 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 ask for an additional $1,000,000 to allow for the funding of four more state programs, bringing the total State grant allocation to just over $7,000,000.

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 $5,000,000 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 is needed to help reduce government expenditures and increase productivity, independence, and community integration. However, advocates must possess specialized skills, and their work is often time-intensive. An increased appropriation in this area would ensure that each P&A can move towards providing a significant PATBI program with appropriate staff time and expertise.

CDC – National Injury Center - $10 million (+ $5 million) for the Centers for Disease Control and Prevention TBI Registries and Surveillance, Brain Injury Acute Care Guidelines, Prevention and National Public Education/Awareness.

The Centers for Disease Control and Prevention's National Injury Center is responsible for assessing the incidence and prevalence of TBI in the United States. The CDC estimates that 2.5 million TBIs occur each year and 5.3 million Americans live with a life-long disability as a result of TBI. The TBI Act as amended in 2014 requires the CDC to coordinate with the Departments of Defense and Veterans Affairs to include the number of TBIs occurring in the military. This coordination will likely increase CDC's estimate of the number of Americans sustaining TBI and living with the consequences.

CDC also funds states for TBI registries, creates and disseminates public and professional educational materials, for families, caregivers and medical personnel, and has recently collaborated with the National Football League and National Hockey League to improve awareness of the incidence of concussion in sports. CDC plays a leading role in helping standardize evidence based guidelines for the management of TBI and $1 million of this request would go to fund CDC's work in this area.

In 2013, the National Academies of Sciences, Engineering, and Medicine (formerly known as the Institute of Medicine, or the IOM) issued a report calling on the CDC to establish a surveillance system that would capture a rich set of data on sports- and recreation-related concussions among 5-21 year olds that otherwise would not be available. To meet this goal, we request an increase of $5 million in the CDC budget to establish and oversee a national surveillance system to accurately determine the incidence of concussions, particularly among the most vulnerable of Americans—our children and youth. In the President's FY 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 on 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 program 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 are 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 researchers.

In order to make this program more comprehensive, Congress should increase funding in FY2017 for NIDILRR's TBI Model Systems of Care program, in order to add one new Collaborative Research Project. 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. Specifically, the Congressional Brain Injury Task Force requests increased funding by $13 million over the next six years to support the TBI Model Systems program:

- Increase funding for the National Data and Statistical Center by $100,000 annually to allow all participants to be followed; when re-competed, increase from $625,000 to $1 million annually;
- Increase funding for centers by $150,000 annually from the current average of $437,500;
- Increase the number of competitively funded centers from 16 to 18; and
- Increase the number of multicenter TBI Model Systems Collaborative Research projects from one to five, each with an annual budget of $1.5 million (current funding is $600,000 each).

We ask that you consider favorably these requests for the Administration for Community Living, the CDC, and the NIDILRR's TBI Model Systems Program 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.

Testimony Prepared by Sonia Grant, Program Director, Heritage Health and Housing for the United State House Committee on Labor, Health and Human Services, and Education, and Related Agencies addressed to the Department of Health and Human Services

April 15, 2015

Heritage Health and Housing is part of a nationwide coalition, the Food is Medicine Coalition, of over 80 food and nutrition services providers, affiliates and their supporters across the country that provide food and nutrition services to people living with HIV/AIDS (PWH) and other chronic illnesses. In our service area we provide 20,000 congregate meals and 12,000 home delivered meals annually. Collectively, the Food is Medicine Coalition is committed to increasing awareness of the essential role that food and nutrition services (FNS) play in successfully treating HIV/AIDS and to expanding access to this indispensable intervention for people living with other severe illnesses.

1.) Why Food and Nutrition Services (FNS) Matter for PWH

While adequate food and nutrition are basic to maintaining health for all persons, good nutrition is crucial for the management of HIV infection. Proper nutrition is needed to increase absorption of medication, reduce side effects, and maintain healthy body weight. Research has identified the virus as an independent risk factor for cardiovascular, liver and kidney disease, cancer, osteoporosis and stroke. Several HIV medications can cause nausea and vomiting and some can affect lab results that test lipids and kidney and liver function. These compounding health effects, caused by the virus and its medications, reinforce the important role a nutrient-rich diet plays in a patient's overall care plan. In addition, providing food and nutrition services can serve to facilitate access and engagement with medical care, especially among vulnerable populations.

The Food and Nutrition Services category within the Ryan White Program includes medical nutritional therapy (MNT) and food and nutrition services (FNS). MNT covers nutritional diagnostic, therapy, and counseling services focused on prevention, delay or management of diseases and conditions, and involves an in-depth assessment, periodic reassessment and intervention provided by a licensed, Registered Dietitian Nutritionist (RDN) outside of a primary care visit. The range of FNS provided through the Ryan White program complements the needs of PWH at any stage of their illness. For those who are most mobile, there are congregate meals, walk-in food pantries and voucher programs. For those whose disease has progressed, home-delivered meals and home-delivered grocery bags complement their medical treatment.

Since 2006, HRSA has included MNT and FNS, provided under the guidance of RDNs, as a clinically effective **core medical service** in the Ryan White Program. These services play a critical role in ensuring that PWH enter and continue in primary medical care, adhere to their medications, and ultimately achieve viral suppression.

2.) FNS as a Care Completion Service Unique to Ryan White

Social and economic interventions, most often in the form of care completion service like food and nutrition services, are fundamental to making health care work for PWH. Support services for PWH are not covered in any comprehensive way by Medicaid or other public insurance initiatives that have been expanded by the Affordable Care Act. As the HIV epidemic in the United States increasingly impacts low-income individuals, support services help stabilize individuals living with or at risk of HIV. When needs are met, and life's emergencies are held at bay, PWH are poised to remain connected to care and treatment.

3.) Access to FNS and the Triple Aim

Access to appropriate food and nutrition services (FNS) are increasingly recognized as key to accomplishing the triple aim of national healthcare reform for PWH.

Better Health Outcomes

When clients get effective FNS and become food secure, they then keep scheduled primary care visits, score higher on health functioning, are at lower risk for inpatient hospital stays and are more likely to take their medicines[i]. Studies show both the health benefits of access to MNT and/or nutrition counseling for people with HIV infections[ii] and the resulting decreases in their healthcare costs. Compare these outcomes to PWH who are food insecure, who have:

- Lower CD4 counts & lower likelihoods of having undetectable viral loads[iii]
- More ER visits[iv] & increased morbidity and mortality[v]
- More missed primary care appointments & reduced use of antiretroviral therapy[vi].

Lower Healthcare Costs

Millions of dollars in healthcare expenditures are saved through the provision of FNS to PWH. A recent study comparing participants in a medically-tailored FNS program vs. a control group within a local managed care organization found that average monthly healthcare costs for PWH fell 80% in first three months after receiving FNS[vii]. If hospitalized, nourished clients' costs were 30% lower, their hospital length of stay was cut by 37% and they were 20% more likely to be able to be discharged to their homes rather than a more expensive institution[viii]. Furthermore, FNS are a very inexpensive intervention. For each day in a hospital saved, you can feed a person a medically-tailored diet for half a year.

Improved Patient Satisfaction

Studies show nutrition counseling improves quality of life[ix]. Members overwhelmingly report that our services help them live more independently, eat more nutritiously and manage their medical treatment more effectively.

4.) FNS and the National HIV/AIDS Strategy (NHAS)

Access to FNS for PWH is fundamental to fulfilling the goals of the NHAS.

- **NHAS Goal: Reducing new HIV infections:** PWH who are food insecure are less likely to have undetectable viral loads in a statistically significant way. Undetectable viral loads prevent transmission 96% of the time[x], thus, FNS is key to prevention[xi].
- **NHAS Goal: Increasing access to care and improving health outcomes for people living with HIV:** PWH who receive effective FNS are more likely to keep scheduled primary care

visits, score higher on health functioning, are at lower risk for inpatient hospital stays and are more likely to take their medicines[xii].

- **NHAS Goal: Reducing HIV-related disparities and health inequities:** By providing FNS to PWH who are in need largely because of poverty, we improve health outcomes, thereby reducing health disparities[xiii].
- **NHAS Goal: Achieving a more coordinated national response to the HIV epidemic:** There remains a tremendous variation by state in coverage of food and nutrition services both inside and outside of Ryan White, making support for Ryan White HIV Program all the more needed. Ultimately, if we are going to achieve a more coordinated national response to the HIV epidemic and our quest to reduce healthcare spending nationwide, FNS must be included in all healthcare reform efforts, including Ryan White and the ACA.

Conclusion

We are deeply aware of the difficult decisions that face the members of the Committee in the current fiscal environment. Yet, research shows that investment in FNS, with the great return in prevention and retention in HIV care, are vital to lowering the number of new infections in the domestic HIV epidemic and ultimately reducing healthcare costs and preserving healthcare resources for the future. A client's diet can literally have life and death consequences. When people are severely ill, good nutrition is one of the first things to deteriorate, making recovery and stabilization that much harder, if not impossible. Early and reliable access to medically-appropriate FNS helps PWH live healthy and productive lives, produces better overall health outcomes and reduces health care costs.

Along with our colleagues, we appreciate the opportunity to offer this testimony regarding the FY 2017 Appropriations process. We are also pleased to offer our assistance and expertise, including information from our Research Library.

Thank you.

Sonia Grant
Program Director
Heritage Health & Housing
416 West 127th Street,
New York NY 10027
212- 866- 2600
sgrant@heritagenyc.org

---

[i] Aidala A, Yomogida M, Vardy Y & the Food & Nutrition Study Team. Food and Nutrition Services, HIV Medical Care, and Health Outcomes. New York State Department of Health: Resources for Ending the Epidemic, 2014. Available at https://www.health.ny.gov/diseases/aids/ending_the_epidemic/docs/key_resources/housing_and_supportive_services/chain_factsheet3.pdf

[ii] Academy of Nutrition and Dietetics (formerly American Dietetic Association). HIV/AIDS Nutrition Evidence Analysis Project at http://www.adaevidencelibrary.com/conclusion.cfm?conclusion_statement_id=250707 Accessed 29 July 2012.

[iii] Aidala A., Yomogida M., and the HIV Food & Nutrition Study Team (2011); Singe AW,Weiser SD, McCoy, SI. Does Food Insecurity Undermine Adherence to Antiretroviral Therapy? A Systematic Review. AIDS Behav (2015) 19:1510–1526.

[iv] Ibid.

[v] Anema A, Chan K, Yip B, Weiser S, Montaner JSG, Hogg RS. Impact of food insecurity on survival among HIV-positive injection drug users receiving antiretroviral therapy in a Canadian cohort. 141st APHA Annual Meeting, Nov. 2-6, 2013. Boston, MA. Abstract #: 290277

[vi] Aidala A., Yomogida M., and the HIV Food & Nutrition Study Team (2011).

[vii] Gurvey J, Rand K, Daugherty S, Dinger C, Schmeling J, Laverty N. Examining Health Care Costs Among MANNA Clients and a Comparison Group. J Prim Care Community Health. (2013) 4:311-317

[viii] Ibid.

[ix] Rabeneck L, Palmer A, Knowles JB, Seidehamel RJ, Harris CL, Merkel KL, Risser JMH, Akrabawi SS. A randomized controlled trial evaluating nutrition counseling with or without oral supplementation in malnourished HIV-infected patients. J Am Diet Assoc. (1998) 98: 434-438;Schwenk A, Steuck H, Kremer G. Oral supplements as adjunctive treatment to nutritional counseling in malnourished HIV-infected patients: randomized controlled trial. Clinical Nutrition (1999) 18(6): 371-374.

[x] M. S. Cohen *et al.*, Prevention of HIV-1 Infection with Early Antiretroviral Therapy. N. Engl. J. Med.(2011) 365, 493-505 . HPTN 052

[xi] Palar K, Laraia B, Tsai A, Weiser SD Food insecurity is associated with sexually transmitted infections and HIV serostatus among low income adults in the National Health and Nutrition Examination Survey (NHANES) (1999-2010). Presented at the American Public Health Association 141st Annual Meeting, Boston, MA, November 5, 2013.

[xii] Aidala A, Yomogida M, Vardy Y & the Food & Nutrition Study Team. Food and Nutrition Services, HIV Medical Care, and Health Outcomes. New York State Department of Health: Resources for Ending the Epidemic, 2014. Available at

xiii Weiser SD, Frongillo EA, Ragland K, Hogg RS, Riley ED, Bangsberg DR. Food insecurity is associated with incomplete HIV RNA suppression among homeless and marginally housed HIV-infected individuals in San Francisco. J Gen Intern Med. (2009) 24(1):14-20.

Luke Byram

Board Member

Center for Independence

Prepared for the House Appropriations Subcommittee on Labor, Health and Human Services, Education, and Related Agencies

Dear Chairman Cole, Ranking Member DeLauro, Vice Chair Womack, and Members of the Subcommittee,

I am writing to support the National Council on Independent Living's request for Congress to reaffirm your commitment to the more than 57 million Americans with disabilities by increasing funding in the HHS appropriations for Centers for Independent Living (CILs). I am asking that you increase funding by $200 million, for a total of $301 million for the Independent Living line item in FY 2017.

CILs are cross-disability, non-residential, community-based, nonprofit organizations that are designed and operated by individuals with disabilities. CILs are unique in that they are directly governed and staffed by people with all types of disabilities, including people with mental, physical, sensory, cognitive, and developmental disabilities. Each of the 365 federally funded centers provides five core services: information and referral, individual and systems advocacy, peer support, independent living skills training, and transition services, which were added with the passage of the Workforce Innovation and Opportunity Act (WIOA). From 2012-2014, CILs provided the core services to nearly 5 million people with disabilities, and provided additional services such as housing assistance, transportation, personal care attendants, and employment services to hundreds of thousands of individuals. During this same period, prior to transition

being added as a core service, CILs transitioned 13,030 people with disabilities from nursing homes and other institutions into the community.

Transition services were added as a fifth core service with the 2014 reauthorization of the Rehabilitation Act within the Workforce Innovation and Opportunity Act. Transition services include the transition of individuals with significant disabilities from nursing homes and other institutions to home and community-based residences with appropriate supports and services, assistance to individuals with significant disabilities at risk of entering institutions to remain in the community, and the transition of youth with significant disabilities to postsecondary life. This core service is vital to achieving full participation for people with disabilities.

Every day, CILs are fighting to ensure that people with disabilities gain and maintain control over our own lives. We know that this cannot occur when people reside in institutional settings. Opponents of deinstitutionalization say that allowing people with disabilities to live in the community will result in harm. We know that the 13,030 people with disabilities who CILs successfully transitioned out of nursing homes and institutions from 2012-2014 prove otherwise. Additionally, when services are delivered in an individual's home, the result is a tremendous cost savings to Medicaid, Medicare, and states. Community-based services enable people with disabilities to become less reliant on long-term government supports, and they are significantly less expensive than nursing home placements. We are grateful that Congress demonstrated their understanding and support for community-based services when WIOA was passed and transition was added as a fifth core service.

Since transition services were added as a core service, the need for funding is critical. Furthermore, CILs need additional funding to restore the devastating cuts to the Independent Living program, make up for inflation costs, and address the increased demand for independent living services. In 2016, the Independent Living Program is receiving $2.5 million less in funding than it was in 2010. It is simply not possible to meet the increasing demand for services and effectively provide transition services without additional funding. Increased funding should be reinvested from the billions currently spent to keep people with disabilities in costly Medicaid nursing homes and institutions and out of mainstream society.

Centers for Independent Living play a crucial role in the lives of people with disabilities, and work tirelessly to ensure that people with disabilities have a real choice in where and how they live, work, and participate in the community. Examples of how CIL's support its consumers is through applying for SSI/SSDI Social Security, providing education regarding college and employment, systems advocacy, share education opportunities for inclusive emergency preparedness, education about transportation and transition for youth from high school to post-secondary goals. Many CIL's are required to provide services with limited resources or no funding what so ever. It is vitally important to adequately fund CIL's so the Centers can provide these necessary services with the increase in funding. Additionally, CILs are an excellent service and a bargain for America, keeping people engaged with their communities and saving taxpayer money. NCIL is dedicated to increasing the availability of the invaluable and extremely cost-effective services CILs provide, and they have submitted written testimony with a similar request. I strongly support NCIL's testimony.

Testimony of Clifford V. Harding, M.D., Ph.D., on behalf of
The American Association of Immunologists (AAI),
Submitted to the House Appropriations Subcommittee on Labor, Health and Human Services, Education, and Related Agencies,
Regarding the Fiscal Year (FY) 2017 Budget for the National Institutes of Health
April 11, 2016

The American Association of Immunologists (AAI), the world's largest professional society of research scientists and physicians who study the immune system, respectfully submits this testimony regarding fiscal year (FY) 2017 appropriations for the National Institutes of Health (NIH). ***AAI recommends an appropriation of at least $35 billion for NIH for FY 2017*** to fund new and ongoing research, stabilize and strengthen the biomedical research enterprise, and encourage the world's most talented scientists, trainees, and students to pursue biomedical research careers in the United States.

The Importance of Immunology and the Immune System

"[I]mmunology kind of transcends it all." So said Senator Richard Shelby (R-AL), a senior member of the Senate Appropriations Committee and its subcommittee on Labor, Health and Human Services, Education, and Related Agencies, during the committee's April 2, 2014, hearing on the FY 2015 budget request for NIH.[1] What Senator Shelby correctly noted is the extraordinary importance – and nearly unlimited potential – of the immune system. And the more we learn, the more we realize that what was true in 2014 is even more true today.

As the body's primary defense against viruses, bacteria, parasites and carcinogens, the immune system can protect its host from a wide range of infectious diseases and from many chronic illnesses, including cancer, Alzheimer's disease, and cardiovascular disease. But the immune system can underperform, leaving the body vulnerable to infections such as influenza, Zika virus, HIV/AIDS, tuberculosis, malaria, and the common cold. It can also become overactive, attacking normal organs and tissues, and causing autoimmune diseases including allergy, asthma, inflammatory bowel disease, lupus, multiple sclerosis, rheumatoid arthritis, and type 1 diabetes. Understanding how the immune system works and how it may be harnessed to help prevent, treat, or cure disease: this is the mission of immunologists as we strive to protect people and animals from chronic and acute diseases and from natural or man-made infectious organisms (including plague, smallpox and anthrax) that could be used as bioweapons.

Recent Immunological Advances Provide Great Hope for Tomorrow

1. New potential treatments for hard-to-treat cancers

Cancer immunotherapies mobilize an individual's immune system to destroy cancer cells without harming healthy cells. Less toxic than standard chemotherapy and radiation, immunotherapies have already been approved for some cancers, including lymphoma and melanoma. Until recently, however, immunotherapy had not shown great efficacy against some hard-to-treat cancers, like non-small cell lung cancer. The 2015 approval of Nivolumab

and Pembrolizumab (anti PD-1 therapy)[2] was, therefore, a landmark event for the treatment of lung cancer. Because this therapy specifically blocks the PD-1/PD-L1 pathway that prevents T cells from killing tumor cells, it improves the immune system's ability to combat cancer.[3]

2. Using the immune system to control HIV infection in HIV-positive patients

A recent NIH-funded study demonstrated how the immune systems of HIV-positive "elite controllers," people whose natural immunity controls HIV infection, produce antibodies that have the potential to be developed to treat others infected with HIV.[4] In this Phase I clinical trial, copies of the protective antibodies produced by elite controllers successfully reduced HIV viral levels when transferred to other HIV-positive patients. This method of harnessing "broadly neutralizing antibodies"[5] can potentially be used more widely against other viruses, protecting whole populations from dangerous infections until vaccines are available.

3. Preventing and treating emerging infectious diseases

With increased globalization and worldwide travel, emerging infectious diseases can create a serious health threat locally as well as an international public health crisis, as evidenced by the recent Ebola virus epidemic in Africa, outbreak of dengue fever in Hawaii,[6] and Zika virus outbreaks in Latin America, Central America, the Caribbean, and the U.S. territories.[7] It is essential, therefore, that NIH continually fund basic research on pathogens and the host response to pathogens, as well as potential medical interventions, in order to be able to prevent and respond to both current and future epidemics.

Because NIH has long supported such basic and clinical research, we have made progress on a vaccine against the Ebola virus,[8] which killed more than 11,300 people in West Africa in 2014-2015.[9] Last month, NIH announced that an experimental vaccine against dengue fever had protected all of its recipients, an important advance in the fight against a disease that infects 390 million people worldwide each year.[10] And because the dengue virus is in the same virus family as the Zika virus, scientists are applying what they have learned from dengue to their efforts to develop a vaccine for Zika,[11] which is linked to both microcephaly and Guillain-Barré syndrome.[12] Zika is of increasing international concern due to a recent surge in the number of cases, particularly in Brazil, where more than 3,000 newborns have been affected thus far.[13]

NIH's Essential Role in the Research Enterprise

As the nation's main funding agency for biomedical and behavioral research, NIH supports the work of "more than 300,000 members of the research workforce, including 35,000 principal investigators" located at universities, medical schools, and other research institutions in all 50 states and the District of Columbia.[14] More than 80% of its budget supports the work of these "extramural" scientists through almost 50,000 grants, while about 10% of the budget supports roughly 6,000 "intramural" researchers and clinicians who work at NIH research and clinical facilities in Maryland, Arizona, Massachusetts, Michigan, Montana and North Carolina.[15] NIH funding strengthens the economies of the communities and states where these researchers live and work; in 2014, it supported more than 400,000 jobs across the United States.[16]

NIH also provides irreplaceable scientific leadership to the national and international biomedical research communities. NIH personnel and policies are essential to the coordination of scientists and scientific projects from academia and government,[17] and to fostering important collaborations with industry, whose own advances in drug and medical device development rely heavily on NIH-funded discoveries.[18]

Recent Funding Boost Eased, But Did Not Eliminate, Erosion of NIH Purchasing Power

A $2 billion boost in NIH funding in FY 2016, generously provided by this subcommittee and the Congress, has helped restore some of the loss in NIH's purchasing power that had resulted from years of inadequate budgets eroded further by biomedical research inflation.[19] Although AAI is extremely grateful for this funding increase, NIH's purchasing power remains more than 19% below what it was in FY 2003.[20] In addition to limiting the advancement of important research and the potential treatments or cures that might have been discovered, these funding constraints continue to have a deleterious impact on many productive researchers: some are being forced to lay off staff or close their labs entirely, while others are moving overseas, where support for biomedical research continues to grow.[21] Perhaps most importantly, inadequate funding is deterring many of our most promising young people from pursuing careers in biomedical research; they witness their mentors' unrelenting and time consuming search for funding, rather than their conduct of research or teaching of the nation's future researchers, doctors, inventors and innovators. Regular and predictable funding increases for NIH would provide the stability that science, scientists, and the scientific enterprise urgently need.

Conclusion

AAI greatly appreciates the subcommittee's strong bipartisan support for NIH and biomedical research, and for the reasons described above, recommends an appropriation of *at least $35 billion* for NIH in FY 2017.

---

[1] http://www.appropriations.senate.gov/hearings/fy15-nih-budget-request.

[2] http://www.fda.gov/Drugs/InformationOnDrugs/ApprovedDrugs/ucm466576.htm; http://www.fda.gov/Drugs/InformationOnDrugs/ApprovedDrugs/ucm465650.htm.

[3] Chen, L and Han, X. 2015. Anti–PD-1/PD-L1 therapy of human cancer: past, present, and future. *The Journal of Clinical Investigation* 125: 3384-3391.

[4] Caskey, M. *et al.* 2015. Viraemia suppressed in HIV-1 infected humans by broadly neutralizing antibody 3BNC117. *Nature* 522: 487.

[5] "In first human study, new antibody therapy shows promise in suppressing HIV Infection." *Newswire.* http://newswire.rockefeller.edu/2015/04/08/in-first-human-study-new-antibody-therapy-shows-promise-in-suppressing-hiv-infection/.

[6] Dengue "is endemic in Puerto Rico and in many popular tourist destinations in Latin America, Southeast Asia and the Pacific islands." http://www.cdc.gov/dengue/.

[7] http://www.cdc.gov/zika/geo/index.html.

[8] http://www.niaid.nih.gov/news/newsreleases/Archive/2003/pages/ebolahumantrial.aspx; https://www.niaid.nih.gov/news/newsreleases/2016/Pages/CROI-ZMapp.aspx.

[9] http://www.cdc.gov/vhf/ebola/outbreaks/2014-west-africa/case-counts.html.

[10] http://www.nih.gov/news-events/news-releases/experimental-dengue-vaccine-protects-all-recipients-virus-challenge-study. The experimental vaccine was developed primarily by NIH scientists at the NIAID Laboratory of Infectious Diseases, with assistance from scientists at the FDA Center for Biologics Evaluation and Research.

[11] Ibid.

[12] http://www.cdc.gov/zika/about/gbs-qa.html; http://www.cdc.gov/zika/pregnancy/question-answers.html.

[13] Maron, Dina Fine. Surge in Babies Born with Small Heads. *Scientific American.* http://www.scientificamerican.com/article/what-s-behind-brazil-s-alarming-surge-in-babies-born-with-small-heads/.

[14] http://www.nih.gov/sites/default/files/about-nih/strategic-plan-fy2016-2020-508.pdf; http://www.nih.gov/about-nih/what-we-do/budget.

[15] Ibid; https://www.training.nih.gov/resources/intro_nih/other_locations.

[16] Ehrlich, Everett. NIH's Role in Sustaining the U.S. Economy. *United for Medical Research,* http://www.unitedformedicalresearch.com/wp-content/uploads/2015/10/UMR-NIH-FY2014-Economic-Update-10.01.15.pdf.

[17] AAI strongly opposes policies that limit government scientists' ability to attend privately sponsored scientific meetings and conferences and believes that "the rules have ... made government scientists feel cut off from the rest of the scientific community, wreaked havoc with their ability to fulfill professional commitments, and undermined the morale of some of the government's finest minds." *Written Testimony (Amended) of Lauren G. Gross, J.D., on behalf of The American Association of Immunologists (AAI), Submitted to the Senate Homeland Security and Governmental Affairs Committee for the Hearing Record of January 14, 2014: "Examining Conference and Travel Spending Across the Federal Government"* (http://aai.org/Public_Affairs/Docs/2014/AAI_Testimony_to_Senate_HSGAC_01142014.pdf).

[18] According to Dr. Marc Tessier-Lavigne, former chief scientific officer at Genentech and current president of The Rockefeller University, "if we invest adequately in basic biomedical research, we can create the knowledge that will in turn trigger private-sector investment to develop therapies to conquer such diseases....For every drug approved by the FDA at the top of the pyramid, the foundation consists of dozens of insights into diseases generated over a period of decades, largely through federal funding of basic, knowledge-driven research." *Written Testimony of Dr. Marc Tessier-Lavigne, Submitted to the House Committee on Science, Space, and Technology, Subcommittee on Research and Technology, for the Hearing Record of July 17, 2014: "Policies to Spur Innovative Medical Breakthroughs from Laboratories to Patients."* https://science.house.gov/sites/ republicans.science.house.gov/files/documents/HHRG-113-SY14-WState-MTessierLavigne-20140717.pdf

[19] Federation of American Societies for Experimental Biology. U.S. Biological and Medical Research Fell for Over a Decade. http://www.faseb.org/Portals/2/PDFs/opa/2016/Factsheet_Restore_NIH_Funding.pdf

[20] Federation of American Societies for Experimental Biology. NIH Research Funding Trends: FY 1995-2015. http://www.faseb.org/Science-Policy-and-Advocacy/Federal-Funding-Data/NIH-Research-Funding-Trends.aspx

[21] Moses, H., *et al.* 2015. The Anatomy of Medical Research: US and International Comparisons. *JAMA* 313: 174-189. According to Moses *et al.*, while U.S. funding for biomedical and health services research increased at a rate of 6 percent per year from 1994-2004, it decreased to just 0.8 percent annually from 2004-2012.

Submission by MEadvocacy.org
Prepared for House Committee on Appropriations Subcommittee on Labor, Health and Human Services, Education, and Related Agencies.

Dear Ladies and Gentlemen of the Committee:

I am, Mary Ann Kindel, a member of the advisory committee of MEadvocacy.org (1), a project of the non-profit organization May12.org. MEadvocacy is asking Health and Human Services to fund $250 million for research into the devastating disease myalgic encephalomyelitis (ME).

There is an urgent need for a systemic overhaul at the Department of Health and Human Services (HHS), including the National Institutes of Health (NIH) and the Centers for Disease Control (CDC), in regard to its funding and handling of the disease ME.

Myalgic encephalomyelitis is is chronic, serious disabling, neuroimmune disease that affects an estimated one million American men, women and children in the U.S. Yet, the past three decades, since the Lake Tahoe outbreak where the disease was redefined, there have been few biomedical scientific advances and no FDA approved treatments for this heavily burdened disease. This is due to the fact HHS, NIH and CDC have had an institutional bias leading to marginalization, neglect, underfunding and mistreatment of this patient community.

Advances in the science of the disease have been repeatedly squashed by the gross lack of funding by NIH for the disease. In addition, misinformation and badly outdated information published by the CDC, along with the lack of education about the disease in medical schools, has caused a dearth of palliative care for patients nationwide. Most importantly, after 30 years, we still are not any closer to finding an FDA approved treatment or cure to help the estimated 17 million ME patients worldwide.

MEadvocacy.org is a non-profit grassroots movement of advocates and patients who are rising up and saying it is time for a change. We are lawyers, laborers, teachers, students, fathers, mothers, and children. Our productive lives have been cut short by this disease and we currently have no hope of treatment or cure. We have had enough and are saying, "No More!"

ME Incidence and Prevalence:

ME, also known in the U.S. as chronic fatigue syndrome (CFS) and myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), sickens an estimated 1 million people in the U.S. and 17 million worldwide. A majority of patients are disabled, unable to work, attend school or participate in activities of daily life. A quarter, an estimated 250,000 people, are so severely affected as to render them bedbound, unable to care for themselves.

ME History, Criteria and Name:

ME has a long history, appearing worldwide in epidemic and endemic forms. A 1955 outbreak in London resulted in what Dr. A. Melvin Ramsay (2) described it as an infectious neuromuscular illness and formally used the term "myalgic encephalomyelitis." Disregarding this, the CDC broadly redefined the disease and renamed it the marginalizing name chronic fatigue syndrome (CFS) in response to 1985 cluster outbreaks of the disease in Incline Village, Nevada and Lyndonville, New York. This redefinition resulted in three decades of confused research findings rather than answers to the cause and treatment of this disease. In addition, the undignified name and poor criteria causes stigmatization and marginalization of patients.

Disease Burden and Funding:

Some ME patients have died prematurely from complications of ME. Others have died at their own hands due to the severity and length of their suffering without proper palliative care, as well as dismissal and stigmatization by the medical community. If we do not act on behalf of these severely affected patients, we are complicit in their suffering and untimely deaths. The patients will no longer carry this burden quietly and we are looking at Congress to require HHS to properly fulfill their duty to ME sufferers.

In 2009, Dr. Nancy Klimas, the director of AIDS research at the Miami Veterans Affairs Medical Center stated:

"My H.I.V patients for the most part are hale and hearty thanks to three decades of intense and excellent research and billions of dollars invested. Many of my CFS patients, on the other hand, are terribly ill and unable to work or participate in the care of their families. I split my clinical time between the two illnesses, and I can tell you if I had to choose between the two illnesses, (in 2009) I would rather have HIV. But CFS, which impacts a million people in the United States alone, has had a small fraction of the research dollars directed towards it." (3)

In the intervening 7 years, nothing has changed. It is very clear that real change at HHS regarding this disease will not come about naturally. We have come to you, the subcommittee for Labor, Health and Human Services, Education, and Related Agencies, for help in addressing this dire need for oversight and investigation.

It is estimated that the burden to the economy for ME is between $17 to $24 billion, yet NIH funding for research has stagnated at a mere $5 to $6 million a year, less than funding for hay fever. HHS has placed funding for ME at the rock bottom of their funding budget list (4). The yearly allocation for ME/CFS is a fraction of what other similarly burdened diseases receive. Dr. Francis Collins, the director of NIH, has promised increased help but the proposed funding for

ME/CFS is only $7 million.

HHS/NIH funding data for 2015 for several diseases: HIV/AIDS $3 billion; M.S. - $94 million; Parkinson's $146 million; Alzheimer's $589 million; ME/CFS $6 million.

The great divide between NIH funding for ME and other diseases cannot be explained away. Simply advising and recommending that NIH increase funding for ME, has not worked. The Secretaries of Health and Human Services have not responded to most of the nearly 100 recommendations made by the Chronic Fatigue Syndrome Advisory Committee (CFSAC) (5) during the past ten years. It ignored specific requests by CFSAC, medical experts, patient advocates, patients and their families to adopt ME expert authored, well defined criteria for the disease and calls for RFAs and increases in NIH funding.

HHS did not heed the call by President Obama as a result of a call out at a townhall meeting by the wife of a patient. It has not listened to the many recommendations by this Appropriations Committee over the past twenty years. In order to fund ME on par with MS, a similarly serious disease, ME would need **$250 million** a year to bring them on par with other similarly burdened diseases yet, gets a mere **$6 million**. This is just on a premise of equality, not equity. If evaluated based on equity, a disease with no FDA approved treatment and an abysmal quality of life (lower than AIDS and MS), it should be getting much more funding to bring it up to par. To be equitable ME should be funded at greater than $3 billion.

We need a different approach and a complete overhaul at all agency levels. We need an investigation by Congress into the mishandling and neglect of ME by HHS, NIH and CDC and active, ongoing Congressional oversight until HHS' negative institutional bias is rectified. We are therefore coming to you for help in this matter.

The following are the recommendations and goals that we at MEadvocacy.org feel the Appropriations Committee needs to require that HHS meet, in order to bring myalgic encephalomyelitis back on par with other similarly burdened diseases:

1. Fund biomedical research for ME commensurate with its severity and burden to patients and the economy. We are asking for specific funding in the amount of **$250 million**, the amount we believe is needed to bring ME on par with other similarly burdened diseases. HHS should clearly allocate funds to study patients from past ME cluster outbreaks as well as the study of the epidemiology of patients with severe ME. The additional funding needed for ME might be accomplished by means of a sliding scale of allocation from other diseases related to immune, cognitive and nervous system dysfunctions.

2. Heed the ME stakeholders' request to adopt the diagnostic and research

criteria authored by those experienced in the disease, namely the 2003 **Canadian Consensus Criteria** (CCC) (6), which has been adopted by the International Association of Chronic Fatigue Syndrome/ Myalgic Encephalomyelitis (IACFS/ME) (7). In a letter to the Secretary of HHS, 50 experts (8) in the disease declared their consensus agreement to adopt the CCC. This was endorsed by a letter signed by 171 advocates (9) as well as a petition (10) signed by over 6,000 patients. The 2011 revision known as the International Consensus Criteria (ICC) (11) would be an alternatively acceptable criteria for adoption.

3. Retain the historical name for this disease, **myalgic encephalomyelitis**, which has been coded since 1969 by the World Health Organization under neurological disease with the code G93.3 and is similarly coded in the 2015 U.S. ICD Codes as U.S. ICD-10-CM.

Additionally, we request that the Appropriation Committee recommends HHS:

A- Ensure that NIH completes their 2015 promise of placing ME into the National Institute of Neurological Disorders and Stroke (NINDS), which also manages similar neuroimmune diseases such as MS, fibromyalgia, and Lyme Disease. The Office of Research on Women's Health, where ME is currently housed, is entirely inappropriate for a disease which also strikes men and children.

B- Provide opportunities for **dissemination of information** through the development of a curriculum for all U.S. based medical schools, as well as physician continuing education, about ME as defined solely by disease experts, in order to provide the tools needed for physicians and other medical professionals to appropriately recognize and treat this disease. Currently, this would mean using either the 2003 Canadian Consensus Criteria or the 2011 International Consensus Criteria, not the overly broad criteria developed by the non-expert IOM panel which the CDC is defiantly implementing in their educational materials. In addition, the CCC (6) or ICC Primer (11) should be widely distributed and made available to clinicians, particularly primary care physicians, nationwide in order to facilitate the best care for their ME patients.

C- **Partner openly and transparently** with stakeholders within one year to establish a comprehensive, aggressive and fully funded cross agency strategy and implementation plan, with well defined objectives and milestones, and to develop a plan to monitor progress and provide for Congressional oversight.

"We've documented, as have others, that the level of functional impairment in people who suffer from CFS is comparable to multiple sclerosis, AIDS, end stage renal failure, chronic obstructive pulmonary disease. The disability is equivalent to that of some well known, very severe medical conditions." – Dr. William Reeves, former CDC Chief of Viral Diseases Branch (2006 CDC Press Conference)

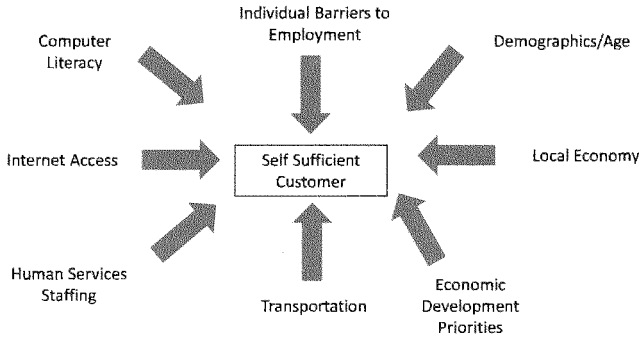
Links:
1) http://www.meadvocacy.org
2) http://www.name-us.org/DefintionsPages/DefRamsay.htm
3) http://consults.blogs.nytimes.com/2009/10/15
4) https://report.nih.gov/categorical_spending.aspx
5) http://www.hhs.gov/advcomcfs/recommendations/index.html#
6)http://www.name--
us.org/DefintionsPages/DefinitionsArticles/ConsensusDocument%20Overview.pd
f
7) http://www.iacfsme.org
8)https://dl.dropboxusercontent.com/u/89158245/Case%20Definition%20Letter%
20Sept%2023%202013.pdf
9)
https://thoughtsaboutme.files.wordpress.com/2013/10/sebelius_letter_advocates
2.pdf
10)https://secure.avaaz.org/en/petition/Stop_the_HHSIOM_contract_and_accept
_the_CCC_definition_of_ME /?pv=4
11)http://www.name--
us.org/DefintionsPages/DefinitionsArticles/2012_ICC%20primer.pdf

FY 2017 Testimony for the Record

Submitted by: Daniel P. McDermott, Executive Director, Upper Shore Workforce Investment Board.

Reference: Workforce Innovation and Opportunity Act funding level.

Testimony: As we work to implement the Workforce Innovation and Opportunity Act, we have learned through focus groups with front line staff that workers face difficulty overcoming structural barriers to employment that are bigger than simply having adequate funding for skill training and skill acquisition. The macro level scenario that job seekers face is best explained by this graphic:



Funding for the Workforce Innovation and Opportunity Act at levels adequate to provide customers with a path to self-sufficiency through job training is crucial. The rate of change in the economy is such that workers are left behind quickly if they are not able to develop skills at the same or a faster rate than the change in the workplace.

Please consider the challenge faced by workers who want and need to change with the economy as funding decisions are made within the House Committee on Appropriations Subcommittee on Labor, Health and Human Services, Education, and Related Agencies.

Thank You.

T.A.R.P.
Center for Independent Living
TARP stands for: Training, Advocacy, Referral, Peer Support

Denise Wardle, Executive Director
1027 Mineral Wells Ave., Suite 3
Paris, TN 38242-4908

Phone: 731.644.0026
denisew@tarp1.org

April 13, 2016

Dear Congress,

I am writing to support the National Council on Independent Living's request for Congress to reaffirm your commitment to the more than 57 million Americans disabilities by increasing funding in the HHS appropriations for Centers for Independent Living (CILs). I am asking that you increase funding by $200 million, for a total of $301 million for the Independent Living line item in FY 2017.

CILs are cross-disability, non-residential, community-based, nonprofit organizations that are designed and operated by individuals with disabilities. CILs are unique in that they are directly governed and staffed by people with all types of disabilities, including people with mental, physical, sensory, cognitive, and developmental disabilities. Each of the 365 federally funded centers provides five core services: information and referral, individual and systems advocacy, peer support, independent living skills training, and transition services, which were added with the passage of the Workforce Innovation and Opportunity Act (WIOA). From 2012-2014, CILs provided the core services to nearly 5 million people with disabilities, and provided additional services such as housing assistance, transportation, personal care attendants, and employment services to hundreds of thousands of individuals. During this same period, prior to transition being added as a core service, CILs transitioned 13,030 people with disabilities from nursing homes and other institutions into the community.

Transition services were added as a fifth core service with the 2014 reauthorization of the Rehabilitation Act within the Workforce Innovation and Opportunity Act. Transition services include the transition of individuals with significant disabilities from nursing homes and other institutions to home and community-based residences with appropriate supports and services, assistance to individuals with significant disabilities at risk of entering institutions to remain in the community, and the transition of youth with significant disabilities to postsecondary life. This core service is vital to achieving full participation for people with disabilities.

Every day, CILs are fighting to ensure that people with disabilities gain and maintain control over our own lives. We know that this cannot occur when people reside in institutional settings. Opponents of deinstitutionalization say that allowing people with disabilities to live in the community will result in harm. We know that the 13,030 people with disabilities who CILs successfully transitioned out of nursing homes and institutions from 2012-2014 prove otherwise. Additionally, when services are delivered in an individual's home, the result is a tremendous cost savings to Medicaid, Medicare, and states. Community-based services enable people with disabilities to become less reliant on long-term government supports, and they are significantly less expensive than nursing home placements. We are grateful that Congress demonstrated their understanding and support for community-based services when WIOA was passed and transition was added as a fifth core service.

Since transition services were added as a core service, the need for funding is critical. Moreover, CILs need additional funding to restore the devastating cuts to the Independent Living program, make up for inflation costs, and address the increased demand for independent living services. In

2016, the Independent Living Program is receiving $2.5 million less in funding than it was in 2010. It is simply not possible to meet the increasing demand for services and effectively provide transition services without additional funding. Increased funding should be reinvested from the billions currently spent to keep people with disabilities in costly Medicaid nursing homes and institutions and out of mainstream society.

Centers for Independent Living play a crucial role in the lives of people with disabilities, and work tirelessly to ensure that people with disabilities have a real choice in where and how they live, work, and participate in the community. Additionally, CILs are an excellent service and a bargain for America, keeping people engaged with their communities and saving taxpayer money. NCIL is dedicated to increasing the availability of the invaluable and extremely cost-effective services CILs provide, and they have submitted written testimony with a similar request. I strongly support NCIL's testimony.

Sincerely,

Denise Wardle, Executive Director

Name Alexa Brill

Title Self-Advocate

Institutional Affiliation (if any)

I am writing to support the National Council on Independent Living's request for Congress to reaffirm your commitment to the more than 57 million Americans disabilities by increasing funding in the HHS appropriations for Centers for Independent Living (CILs). I am asking that you increase funding by $200 million, for a total of $301 million for the Independent Living line item in FY 2017.

CILs are cross-disability, non-residential, community-based, nonprofit organizations that are designed and operated by individuals with disabilities. CILs are unique in that they are directly governed and staffed by people with all types of disabilities, including people with mental, physical, sensory, cognitive, and developmental disabilities. Each of the 365 federally funded centers provides five core services: information and referral, individual and systems advocacy, peer support, independent living skills training, and transition services, which were added with the passage of the Workforce Innovation and Opportunity Act (WIOA). From 2012-2014, CILs provided the core services to nearly 5 million people with disabilities, and provided additional services such as housing assistance, transportation, personal care attendants, and employment services to hundreds of thousands of individuals. During this same period, prior to transition being added as a core service, CILs transitioned 13,030 people with disabilities from nursing homes and other institutions into the community.

Transition services were added as a fifth core service with the 2014 reauthorization of the Rehabilitation Act within the Workforce Innovation and Opportunity Act. Transition services include the transition of individuals with significant disabilities from nursing homes and other institutions to home and community-based residences with appropriate supports and services, assistance to individuals with significant disabilities at risk of entering institutions to remain in the community, and the transition of youth with significant disabilities to postsecondary life. This core service is vital to achieving full participation for people with disabilities.

Every day, CILs are fighting to ensure that people with disabilities gain and maintain control over our own lives. We know that this cannot occur when people reside in institutional settings. Opponents of deinstitutionalization say that allowing people with disabilities to live in the community will result in harm. We know that the 13,030 people with disabilities who CILs successfully transitioned out of nursing homes and institutions from 2012-2014 prove otherwise. Additionally, when services are delivered in an individual's home, the result is a tremendous cost savings to Medicaid, Medicare, and states. Community-based services enable people with disabilities to become less reliant on long-term government supports, and they are significantly less expensive than nursing home placements. We are grateful that Congress demonstrated their understanding and support for community-based services when WIOA was passed and transition was added as a fifth core service.

Since transition services were added as a core service, the need for funding is critical. Moreover, CILs need additional funding to restore the devastating cuts to the Independent Living program, make up for inflation costs, and address the increased demand for independent living services. In

2016, the Independent Living Program is receiving $2.5 million less in funding than it was in 2010. It is simply not possible to meet the increasing demand for services and effectively provide transition services without additional funding. Increased funding should be reinvested from the billions currently spent to keep people with disabilities in costly Medicaid nursing homes and institutions and out of mainstream society.

Centers for Independent Living play a crucial role in the lives of people with disabilities, and work tirelessly to ensure that people with disabilities have a real choice in where and how they live, work, and participate in the community. Additionally, CILs are an excellent service and a bargain for America, keeping people engaged with their communities and saving taxpayer money. NCIL is dedicated to increasing the availability of the invaluable and extremely cost-effective services CILs provide, and they have submitted written testimony with a similar request. I strongly support NCIL's testimony.

Testimony Prepared by David Waters, CEO of Community Servings, for the United States House Committee on Labor, Health and Human Services, and Education, and Related Agencies addressed to the Department of Health and Human Services

April 13, 2015

Community Servings is part of a nationwide coalition, the Food is Medicine Coalition, of over 80 food and nutrition services providers, affiliates and their supporters across the country that provide food and nutrition services to people living with HIV/AIDS (PWH) and other chronic illnesses. In our service area, we provide half a million medically tailored, home delivered meals annually. Collectively, the Food is Medicine Coalition is committed to increasing awareness of the essential role that food and nutrition services (FNS) play in successfully treating HIV/AIDS and to expanding access to this indispensable intervention for people living with other severe illnesses.

1.) Why Food and Nutrition Services (FNS) Matter for PWH

While adequate food and nutrition are basic to maintaining health for all persons, good nutrition is crucial for the management of HIV infection. Proper nutrition is needed to increase absorption of medication, reduce side effects, and maintain healthy body weight. Research has identified the virus as an independent risk factor for cardiovascular, liver and kidney disease, cancer, osteoporosis and stroke. Several HIV medications can cause nausea and vomiting and some can affect lab results that test lipids and kidney and liver function. These compounding health effects, caused by the virus and its medications, reinforce the important role a nutrient-rich diet plays in a patient's overall care plan. In addition, providing food and nutrition services can serve to facilitate access and engagement with medical care, especially among vulnerable populations.

The Food and Nutrition Services category within the Ryan White Program includes medical nutritional therapy (MNT) and food and nutrition services (FNS). MNT covers nutritional diagnostic, therapy, and counseling services focused on prevention, delay or management of diseases and conditions, and involves an in-depth assessment, periodic reassessment and intervention provided by a licensed, Registered Dietitian Nutritionist (RDN) outside of a primary care visit. The range of FNS provided through the Ryan White program complements the needs of PWH at any stage of their illness. For those who are most mobile, there are congregate meals, walk-in food pantries and voucher programs. For those whose disease has progressed, home-delivered meals and home-delivered grocery bags complement their medical treatment.

Since 2006, HRSA has included MNT and FNS, provided under the guidance of RDNs, as a clinically effective **core medical service** in the Ryan White Program. These services play a critical role in ensuring that PWH enter and continue in primary medical care, adhere to their medications, and ultimately achieve viral suppression.

2.) FNS as a Care Completion Service Unique to Ryan White

Social and economic interventions, most often in the form of care completion service like food and nutrition services, are fundamental to making health care work for PWH. Support services for PWH are not covered in any comprehensive way by Medicaid or other public insurance initiatives that have been expanded by the Affordable Care Act. As the HIV epidemic in the United States increasingly impacts low-income individuals, support services help stabilize individuals living with or at risk of HIV. When needs are met, and life's emergencies are held at bay, PWH are poised to remain connected to care and treatment.

3.) Access to FNS and the Triple Aim

Access to appropriate food and nutrition services (FNS) are increasingly recognized as key to accomplishing the triple aim of national healthcare reform for PWH.

Better Health Outcomes

When clients get effective FNS and become food secure, they then keep scheduled primary care visits, score higher on health functioning, are at lower risk for inpatient hospital stays and are more likely to take their medicines[i]. Studies show both the health benefits of access to MNT and/or nutrition counseling for people with HIV infections[ii] and the resulting decreases in their healthcare costs. Compare these outcomes to PWH who are food insecure, who have:

- Lower CD4 counts & lower likelihoods of having undetectable viral loads[iii]
- More ER visits[iv] & increased morbidity and mortality[v]
- More missed primary care appointments & reduced use of antiretroviral therapy[vi].

Lower Healthcare Costs

Millions of dollars in healthcare expenditures are saved through the provision of FNS to PWH. A recent study comparing participants in a medically-tailored FNS program vs. a control group within a local managed care organization found that average monthly healthcare costs for PWH fell 80% in first three months after receiving FNS[vii]. If hospitalized, nourished clients' costs were 30% lower, their hospital length of stay was cut by 37% and they were 20% more likely to be able to be discharged to their homes rather than a more expensive institution[viii]. Furthermore, FNS are a very inexpensive intervention. For each day in a hospital saved, you can feed a person a medically-tailored diet for half a year.

Improved Patient Satisfaction

Studies show nutrition counseling improves quality of life[ix]. Members overwhelmingly report that our services help them live more independently, eat more nutritiously and manage their medical treatment more effectively.

4.) FNS and the National HIV/AIDS Strategy (NHAS)

Access to FNS for PWH is fundamental to fulfilling the goals of the NHAS.

- **NHAS Goal: Reducing new HIV infections:** PWH who are food insecure are less likely to have undetectable viral loads in a statistically significant way. Undetectable viral loads prevent transmission 96% of the time[x], thus, FNS is key to prevention[xi].
- **NHAS Goal: Increasing access to care and improving health outcomes for people living with HIV:** PWH who receive effective FNS are more likely to keep scheduled primary care

visits, score higher on health functioning, are at lower risk for inpatient hospital stays and are more likely to take their medicines[xii].

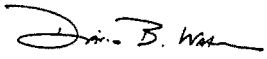
- **NHAS Goal: Reducing HIV-related disparities and health inequities:** By providing FNS to PWH who are in need largely because of poverty, we improve health outcomes, thereby reducing health disparities[xiii].
- **NHAS Goal: Achieving a more coordinated national response to the HIV epidemic:** There remains a tremendous variation by state in coverage of food and nutrition services both inside and outside of Ryan White, making support for Ryan White HIV Program all the more needed. Ultimately, if we are going to achieve a more coordinated national response to the HIV epidemic and our quest to reduce healthcare spending nationwide, FNS must be included in all healthcare reform efforts, including Ryan White and the ACA.

Conclusion

We are deeply aware of the difficult decisions that face the members of the Committee in the current fiscal environment. Yet, research shows that investment in FNS, with the great return in prevention and retention in HIV care, are vital to lowering the number of new infections in the domestic HIV epidemic and ultimately reducing healthcare costs and preserving healthcare resources for the future. A client's diet can literally have life and death consequences. When people are severely ill, good nutrition is one of the first things to deteriorate, making recovery and stabilization that much harder, if not impossible. Early and reliable access to medically-appropriate FNS helps PWH live healthy and productive lives, produces better overall health outcomes and reduces health care costs.

Along with our colleagues, we appreciate the opportunity to offer this testimony regarding the FY 2017 Appropriations process. We are also pleased to offer our assistanee and expertise, including information from our Research Library.

Thank you.



David B. Waters, CEO
Community Servings
18 Marbury Terrace
Jamaica Plain, MA 02130
dwaters@servings.org

---

[i] Aidala A, Yomogida M, Vardy Y & the Food & Nutrition Study Team. Food and Nutrition Services, HIV Medical Care, and Health Outcomes. New York State Department of Health: Resources for Ending the Epidemic, 2014. Available at https://www.health.ny.gov/diseases/aids/ending_the_epidemic/docs/key_resources/housing_and_supportive_services/chain_factsheet3.pdf

[ii] Academy of Nutrition and Dietetics (formerly American Dietetic Association). HIV/AIDS Nutrition Evidence Analysis Project at http://www.adaevidencelibrary.com/conclusion.cfm?conclusion_statement_id=250707 Accessed 29 July 2012.

[iii] Aidala A., Yomogida M., and the HIV Food & Nutrition Study Team (2011); Singe AW,Weiser SD, McCoy, SI. Does Food Insecurity Undermine Adherence to Antiretroviral Therapy? A Systematic Review. AIDS Behav (2015) 19:1510–1526.

[iv] Ibid.

[v] Anema A, Chan K, Yip B, Weiser S, Montaner JSG, Hogg RS. Impact of food insecurity on survival among HIV-positive injection drug users receiving antiretroviral therapy in a Canadian cohort. 141st APHA Annual Meeting, Nov. 2-6, 2013. Boston, MA. Abstract #: 290277

[vi] Aidala A., Yomogida M., and the HIV Food & Nutrition Study Team (2011).

[vii] Gurvey J, Rand K, Daugherty S, Dinger C, Schmeling J, Laverty N. Examining Health Care Costs Among MANNA Clients and a Comparison Group. J Prim Care Community Health. (2013) 4:311-317

[viii] Ibid.

[ix] Rabeneck L, Palmer A, Knowles JB, Seidehamel RJ, Harris CL, Merkel KL, Risser JMH, Akrabawi SS. A randomized controlled trial evaluating nutrition counseling with or without oral supplementation in malnourished HIV-infected patients. J Am Diet Assoc. (1998) 98: 434-438;Schwenk A, Steuck H, Kremer G. Oral supplements as adjunctive treatment to nutritional counseling in malnourished HIV-infected patients: randomized controlled trial. Clinical Nutrition (1999) 18(6): 371-374.

[x] M. S. Cohen *et al.*, Prevention of HIV-1 Infection with Early Antiretroviral Therapy. N. Engl. J. Med.(2011) 365, 493-505 . HPTN 052

[xi] Palar K, Laraia B, Tsai A, Weiser SD Food insecurity is associated with sexually transmitted infections and HIV serostatus among low income adults in the National Health and Nutrition Examination Survey (NHANES) (1999-2010). Presented at the American Public Health Association 141st Annual Meeting, Boston, MA, November 5, 2013.

[xii] Aidala A, Yomogida M, Vardy Y & the Food & Nutrition Study Team. Food and Nutrition Services, HIV Medical Care, and Health Outcomes. New York State Department of Health: Resources for Ending the Epidemic, 2014. Available at

xiii Weiser SD, Frongillo EA, Ragland K, Hogg RS, Riley ED, Bangsberg DR. Food insecurity is associated with incomplete HIV RNA suppression among homeless and marginally housed HIV-infected individuals in San Francisco. J Gen Intern Med. (2009) 24(1):14-20.

Mid-Ohio Board For An Independent Living Environment

John T. Coats, II
Executive Director
Mid-Ohio Board For An Independent Living Environment (MOBILE)

I am writing to support the National Council on Independent Living's request for Congress to reaffirm your commitment to the more than 57 million Americans disabilities by increasing funding in the HHS appropriations for Centers for Independent Living (CILs). I am asking that you increase funding by $200 million, for a total of $301 million for the Independent Living line item in FY 2017.

The Mid-Ohio Board for an Independent Living Environment (MOBILE) is cross-disability, non-residential, community-based, nonprofit organizations that are designed and operated by individuals with disabilities. MOBILE like other CILs across America are unique in that they are directly governed and staffed by people with all types of disabilities, including people with mental, physical, sensory, cognitive, and developmental disabilities. As a CIL, MOBILE is a federally funded center providing five core services: **information and referral, individual and systems advocacy, peer support, independent living skills training, and transition services,** which were added with the passage of the Workforce Innovation and Opportunity Act (WIOA). From 2012-2014, CILs provided the core services to nearly 5 million people with disabilities, and provided additional services such as housing assistance, transportation, personal care

690 South High Street Columbus, Ohio 43206
Office 614 443-5936 • Fax 614 443-5954

attendants, and employment services to hundreds of thousands of individuals. During this same period, prior to transition being added as a core service, CILs transitioned 13,030 people with disabilities from nursing homes and other institutions into the community.

Transition services were added as a fifth core service with the 2014 reauthorization of the Rehabilitation Act within the Workforce Innovation and Opportunity Act. Transition services include the transition of individuals with significant disabilities from nursing homes and other institutions to home and community-based residences with appropriate supports and services, assistance to individuals with significant disabilities at risk of entering institutions to remain in the community, and the transition of youth with significant disabilities to postsecondary life. This core service is vital to achieving full participation for people with disabilities.

Every day, MOBILE and the national network of CILs fight to ensure that people with disabilities gain and maintain control over our own lives. We know that this cannot occur when people reside in institutional settings. Opponents of deinstitutionalization say that allowing people with disabilities to live in the community will result in harm. We know that the 13,030 people with disabilities who CILs successfully transitioned out of nursing homes and institutions from 2012-2014 prove otherwise. Additionally, when services are delivered in an individual's home, the result is a tremendous cost savings to Medicaid, Medicare, and states. Community-based services enable people with disabilities to become less reliant on long-term government supports, and they are significantly less expensive than nursing home placements. We are grateful that Congress demonstrated their understanding and support for community-based services when WIOA was passed and transition was added as a fifth core service.

690 South High Street Columbus, Ohio 43206
Office 614 443-5936 • Fax 614 443-5954

Since transition services were added as a core service, the need for funding is critical. Moreover, CILs need additional funding to restore the devastating cuts to the Independent Living program, make up for inflation costs, and address the increased demand for independent living services. In 2016, the Independent Living Program is receiving $2.5 million less in funding than it was in 2010. It is simply not possible to meet the increasing demand for services and effectively provide transition services without additional funding. Increased funding should be reinvested from the billions currently spent to keep people with disabilities in costly Medicaid nursing homes and institutions and out of mainstream society.

Centers for Independent Living play a crucial role in the lives of people with disabilities, and work tirelessly to ensure that people with disabilities have a real choice in where and how they live, work, and participate in the community. Additionally, CILs are an excellent service and a bargain for America, keeping people engaged with their communities and saving taxpayer money. NCIL is dedicated to increasing the availability of the invaluable and extremely cost-effective services CILs provide, and they have submitted written testimony with a similar request. I strongly support NCIL's testimony.

Submitted By:

John T. Coats, II
Executive Director

690 South High Street Columbus, Ohio 43206
Office 614 443-5936 • Fax 614 443-5954

Institution: National Technical Institute for the Deaf (NTID), Rochester Institute of Technology (RIT)
Submitted by: Dr. Gerard Buckley, President, NTID; Vice President and Dean, RIT
Email: gbuckley@ntid.rit.edu **Phone:** (585) 475-6317

Created by Congress in 1965, the National Technical Institute for the Deaf (NTID) is a "Special Institution" in the federal budget (under the Department of Education) as well as one of nine colleges of RIT, in Rochester, N.Y. We provide a university-level technical and professional education for students who are deaf and hard of hearing, leading to successful careers in high-demand fields for a sub-population of individuals historically facing high rates of unemployment and under-employment. We also provide baccalaureate and graduate-level education for hearing students in professions serving deaf and hard-of-hearing individuals. On behalf of NTID, for FY 2017, I would like to request $70,712,000, for Operations. With our history of successful stewardship of federal funds and an outstanding educational record of service to people who are deaf and hard of hearing, NTID is a federal investment that *works*.

Enrollment:

NTID students study at the associate, baccalaureate, master's and doctoral levels as part of a university (RIT) that includes more than 17,000 hearing students. Truly a national program, NTID has enrolled students from all 50 states. In Fall 2015 (FY 2016), NTID's enrollment was 1,413 students. For FY 2017, NTID anticipates an enrollment near 1,400. NTID's enrollment history over the last 10 years is shown on the next page.

NTID Enrollments: FY 2007 – FY 2016

Fiscal Year	Deaf/Hard-of-Hearing Students				Hearing Students			Grand Total
	Undergrad	Grad RIT	MSSE	Sub-Total	Interpreting Program	MSSE	Sub-Total	
2016	1,167	53	15	1,235	151	27	178	1,413
2015	1,153	44	16	1,213	146	28	174	1,387
2014	1,195	42	18	1,255	147	30	177	1,432
2013	1,269	37	25	1,331	167	31	198	1,529
2012	1,281	42	31	1,354	160	33	193	1,547
2011	1,263	40	29	1,332	147	42	189	1,521
2010	1,237	38	32	1,307	138	29	167	1,474
2009	1,212	48	24	1,284	135	31	166	1,450
2008	1,103	51	31	1,185	130	28	158	1,343
2007	1,017	47	31	1,095	130	25	155	1,250

(In chart above, MSSE: Master of Science in Secondary Education of Deaf/Hard of Hearing; Grad RIT: other graduate programs at RIT.)

NTID Academic Model: NTID offers high quality, career-focused associate degree programs preparing students for well-paying technical careers. NTID also provides transfer associate degree programs to serve our student population seeking bachelor's, master's, and doctoral degrees in the other colleges of RIT. In support of those deaf and hard-of-hearing students enrolled in the other RIT colleges, NTID provides a range of access services (e.g., sign language interpreting, real-time speech-to-text captioning, notetaking) as well as tutoring services. Historically, NTID has followed a direct instruction model for its associate-level classes, with limited need for sign language interpreters, captionists, or other access services. However, the demand for access services has grown recently as associate-level students are requesting communication based on their preferences and as more students enroll in programs at RIT. During FY 2015, 140,230 hours of interpreting were provided – an increase of 20% compared to FY 2010. During FY 2015, 22,241 hours of real-time captioning were provided to

students – a 14% increase over FY 2010. As a result, NTID's FY 2017 funding request recognizes the need to invest in additional access services staff and in research on technologies that might serve as an alternative to traditional access services.

NTID also requires a cooperative education (co-op) component as an integral part of academic programming that prepares students for success in the job market. Last year, 235 students participated in 10-week co-op experiences that augmented their academic studies, refined their social skills, and prepared them for the competitive working world.

Student Accomplishments: NTID deaf and hard-of-hearing students persist and graduate at higher rates than the national persistence and graduation rates for all students at two-year and four-year colleges. Over the past five years, an average of 93% of our graduates found jobs commensurate with their education level. Of our FY 2014 graduates, 94% were employed one year later, with 61% employed in business and industry, 28% in education and non-profits, and 11% in government.

Graduation from NTID has a demonstrably positive effect on students' earnings over a lifetime, and results in a notable reduction in dependence on Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI). In FY 2012, NTID, the Social Security Administration (SSA), and Cornell University examined earnings and federal program participation data for approximately 16,000 deaf and hard-of-hearing individuals who applied to NTID over our entire history. The study showed that NTID graduates, over their lifetimes, are employed at a higher rate and earn more (therefore

paying more in taxes) than students who withdraw from NTID or attend other universities. NTID graduates also participate at a lower rate in SSI and SSDI programs than students who withdrew from NTID.

Using SSA data, at age 50, 78% of NTID deaf and hard-of-hearing graduates with bachelor degrees and 73% with associate degrees report earnings, compared to 58% of NTID deaf and hard-of-hearing students who withdrew from NTID and 69% of deaf and hard-of-hearing graduates from other universities. Equally important is the demonstrated impact of an NTID education on graduates' earnings. At age 50, $58,000 is the median salary for NTID deaf and hard-of-hearing graduates with bachelor degrees and $41,000 for those with associate degrees, compared to $34,000 for deaf and hard-of-hearing students who withdrew from NTID and $21,000 for deaf and hard-of-hearing graduates from other universities.

An NTID education also translates into reduced dependency on federal transfer programs, such as SSI and SSDI. At age 40, less than 2% of NTID deaf and hard-of-hearing associate and bachelor degree graduates participate in the SSI program compared to 8% of deaf and hard-of-hearing students who withdrew from NTID. Similarly, at age 50, only 18% of NTID deaf and hard-of-hearing bachelor degree graduates participate in the SSDI program and 28% of deaf and hard-of-hearing associate degree graduates participate in the SSDI program, compared to 35% of deaf and hard-of-hearing students who withdrew from NTID.

Budget Request Justification: NTID has worked hard to manage its resources carefully and responsibly. NTID actively seeks alternative sources of public and private support, with approximately 28% of NTID's Operations budget coming from non-federal funds, up from 9% in 1970. Since FY 2006, NTID raised more than $22.5 million in support from individuals and organizations. NTID has also recognized that construction funding is limited and planned for critical and long overdue renovations using existing federal and non-federal funds.

NTID's FY 2017 request of $70,712,000 in Operations would allow NTID to admit all qualified students for Fall 2017 enrollment, keep the FY 2017 tuition increase relatively low (3.9%), and continue to offer Grants in Aid to more students. With this funding, NTID can support new academic programs, add staff (sign language interpreters and captionists) in student access services to meet unprecedented demand, and complete much needed capital and renovation projects.

NTID students persist and graduate at higher rates than national rates for all students. NTID graduates have higher salaries, pay more taxes, and depend less on federal SSI/SSDI programs. Our employment rate is 93% over the past five years. Therefore, I ask you to please consider funding our FY 17 request of $70,712,000 for Operations. Likewise, we will continue to demonstrate to Congress and the American people that NTID is a proven economic investment in the future of young deaf and hard-of-hearing citizens.

Dear Representatives:

My name is Kristin Paus, and I am the Information and Referral Advocate at the Lake County Center for Independent Living. I am writing to support the National Council on Independent Living's request for Congress to reaffirm your commitment to the more than 57 million Americans disabilities by increasing funding in the HHS appropriations for Centers for Independent Living (CILs). I am asking that you increase funding by $200 million, for a total of $301 million for the Independent Living line item in FY 2017.

CILs are cross-disability, non-residential, community-based, nonprofit organizations that are designed and operated by individuals with disabilities. CILs are unique in that they are directly governed and staffed by people with all types of disabilities, including people with mental, physical, sensory, cognitive, and developmental disabilities. Each of the 365 federally funded centers provides five core services: information and referral, individual and systems advocacy, peer support, independent living skills training, and transition services, which were added with the passage of the Workforce Innovation and Opportunity Act (WIOA). From 2012-2014, CILs provided the core services to nearly 5 million people with disabilities, and provided additional services such as housing assistance, transportation, personal care attendants, and employment services to hundreds of thousands of individuals. During this same period, prior to transition being added as a core service, CILs transitioned 13,030 people with disabilities from nursing homes and other institutions into the community.

Transition services were added as a fifth core service with the 2014 reauthorization of the Rehabilitation Act within the Workforce Innovation and Opportunity Act. Transition services

include the transition of individuals with significant disabilities from nursing homes and other institutions to home and community-based residences with appropriate supports and services, assistance to individuals with significant disabilities at risk of entering institutions to remain in the community, and the transition of youth with significant disabilities to postsecondary life. This core service is vital to achieving full participation for people with disabilities.

Every day, CILs are fighting to ensure that people with disabilities gain and maintain control over our own lives. We know that this cannot occur when people reside in institutional settings. Opponents of deinstitutionalization say that allowing people with disabilities to live in the community will result in harm. We know that the 13,030 people with disabilities who CILs successfully transitioned out of nursing homes and institutions from 2012-2014 prove otherwise. Additionally, when services are delivered in an individual's home, the result is a tremendous cost savings to Medicaid, Medicare, and states. Community-based services enable people with disabilities to become less reliant on long-term government supports, and they are significantly less expensive than nursing home placements. We are grateful that Congress demonstrated their understanding and support for community-based services when WIOA was passed and transition was added as a fifth core service.

Since transition services were added as a core service, the need for funding is critical. Moreover, CILs need additional funding to restore the devastating cuts to the Independent Living program, make up for inflation costs, and address the increased demand for independent living services. In 2016, the Independent Living Program is receiving $2.5 million less in funding than it was in 2010. It is simply not possible to meet the increasing demand for services and effectively provide

transition services without additional funding. Increased funding should be reinvested from the billions currently spent to keep people with disabilities in costly Medicaid nursing homes and institutions and out of mainstream society.

I have not worked at the Lake County CIL for long, however, as their employee and a person who is disabled, I can attest that Centers for Independent Living play a crucial role in the lives of people with disabilities, and work tirelessly to ensure that people with disabilities have a real choice in where and how they live, work, and participate in the community. Working as I do has opened my eyes to their great impact in the community. Additionally, CILs are an excellent service and a bargain for America, keeping people engaged with their communities and saving taxpayer money. NCIL is dedicated to increasing the availability of the invaluable and extremely cost-effective services CILs provide, and they have submitted written testimony with a similar request. I strongly support NCIL's testimony.

Jack Ferracane, President (2016-2017)
American Association for Dental Research and Friends of NIDCR Public Witness Testimony
Subcommittee on Labor, Health and Human Services and Education,
Department of HHS, National Institutes of Health

April 15, 2016

On behalf of the American Association for Dental Research (AADR) and the Friends of National Institute of Dental and Craniofacial Research (FNIDCR), I am pleased to submit testimony describing our fiscal year 2017 requests, which include at least **$34.5 billion for the National Institutes of Health (NIH) and $452 million for the National Institute of Dental and Craniofacial Research (NIDCR).** We are extremely grateful that last year Congress provided the most significant increases for NIH and NIDCR in over a decade.

In the fiscal year 2017 Labor, Health and Human Services and Education Appropriations bill, we strongly urge Congress to build on this momentum and continue to provide predictable and sustainable funding for NIH and NIDCR this year and beyond. Increasing funding for NIDCR by an approximate nine percent would allow for six percent real growth in this Institute. This increased investment will improve the oral health of the nation, reduce societal costs of dental care and enhance the scientific evidence base for the dental profession. Specifically, increased funding would enable NIDCR to expand its portfolio of work on immunotherapies for oral cancer; research on cleft lip and cleft palate; and address oral health disparities among the aging population.

NIDCR is the largest institution in the world dedicated exclusively to research to improve dental, oral and craniofacial health. The health of the mouth and surrounding craniofacial (skull and face) structures is central to a person's overall health and well-being. Left untreated, oral diseases and poor oral conditions make it difficult to eat, drink, swallow, smile, communicate and maintain proper nutrition. Scientists also have discovered important linkages between periodontal (gum) disease and heart disease, stroke, diabetes and pancreatic cancer.

Investments in NIDCR funded research during the past half century have led to improvements in oral health for millions of Americans through its impact on areas such as community water fluoridation; the implementation of dental sealants to reduce cavities in children; and emerging opportunities to assess the efficacy of a human papilloma virus (HPV) vaccine for oral and pharyngeal cancers.

As a result of these investments, today over 200 million Americans are benefiting from community water fluoridation. The percent of children from 1960-2000 in the US without any dental decay in their permanent teeth has almost tripled from about 25 percent to 70 percent. Absent advances in oral health research in the fight against dental caries (tooth decay) and periodontal diseases there would be an additional 18.6 million Americans aged 45 or older who have lost all of their natural teeth. Perhaps most striking is that since the 1950s the total federal investment in NIH-funded oral health research has saved the American public at least $3 for every $1 invested.

Despite these improvements, however, treating oral health conditions remains extremely costly —with the nation spending $113.5 billion on dental services in 2014. While tooth decay and gum disease are the most prevalent threats to oral health, complete tooth loss, oral cancer and craniofacial congenital anomalies, such as cleft lip and palate, impose massive health and economic burdens on Americans. Below for your reference are additional examples of the important research supported by NIDCR to address some of these topic areas:

- **Point of Care Diagnostics:** Salivary diagnostics are devices that draw and analyze saliva to test for conditions and infections such as HIV, human papillomavirus (HPV), substance abuse, caries, periodontitis and oral cancer. As a result of research supported by NIDCR over the last decade, diagnostics are also showing great promise in screening for systemic diseases such as diabetes, heart disease, lung cancer, ovarian cancer and pancreatic cancer.
- **E-Cigarettes** According to the CDC the use of electronic cigarettes has tripled among middle and high school students in one year. Currently, there is no scientific evidence to support the safety of e-cigarettes, and initial studies indicate that a variety of chemicals and metal particles are produced during the vaporization of nicotine and additives by these devices. To help address this research gap and inform policymakers, NIDCR has recently provided funding to support several new studies to determine the biological and physiological effects of e-cigarette aerosol mixtures. This research will also include the development of new tools and clinically-relevant model systems to assess their effects on oral and periodontal tissues.
- **Precision Medicine:** Precision medicine is an approach for disease prevention and treatment that takes into account people's individual variations in genes, environment and lifestyle. NIDCR supports a diverse precision medicine research portfolio related to diseases and conditions of the dental, oral and craniofacial region including research on cancer, craniofacial developmental disorders and salivary diagnostics. Further, NIDCR is a leader in conducting research within networks composed of individual and group dental practices where most personalized oral health care in the US is provided.
- **Oral Microbiome:** NIDCR funds a community resource providing comprehensive information on over 700 different microbial species present in the oral cavity. To reduce and eliminate oral health disparities, research on the oral microbiome in children will help identify those at increased risk of developing early childhood caries (tooth decay).
- **Enhanced Tissue Regeneration:** NIDCR-funded scientists have developed effective techniques to reduce inflammation and enable the use of stem cells to form new bone and cartilage for oral, dental and craniofacial purposes. The isolation and enrichment of stem cells is also being explored, which would further enhance the cells' ability to regrow bone and cartilage at the sites where it is most needed. NIDCR recently funded a tissue engineering consortium employing multidisciplinary teams to translate basic research into innovative tools and strategies to regenerate damaged and diseased tissues.
- **HPV-Related Oral Cancer:** Scientists predict that oral cancer will be the most common HPV-related cancer by 2020. In fact, HPV is now causing more oral cancers than smoking. But simply identifying the presence of HPV in a mouth swab or a blood draw does not definitively indicate the presence of cancer. More research is needed to

facilitate the early detection of HPV-related oral cancer, as well as enhancing prevention and treatment approaches.

- **Cleft Lip and/or Cleft Palate**: Craniofacial anomalies such as cleft lip and/or cleft palate are among the most common birth defects. Both genetic and environmental factors contribute to oral clefts. Studies supported by NIDCR are providing important new leads about the role genetic factors and gene-environment interactions play in the development of these conditions.
- **Evidenced-Based Practice**: NIDCR supports a National Dental Practice Based Research Network (NDPBRN) that is headquartered at the University of Alabama at Birmingham School of Dentistry. A dental practice-based research network is an investigative union of practicing dentists and their staffs working in concert with academic scientists. The network provides practitioners with an opportunity to propose or participate in research studies that address critical issues that affect oral health care. These studies help to expand the profession's evidence base and further refine the delivery of quality oral health care.
- **Oral Health Disparities:** NIDCR supports a broad portfolio of research strategies to reduce and eliminate oral health disparities. The Institute recently funded a new consortium that will combine health promotion and disease prevention, community-based participation and multilevel interventions to take decisive action to reduce oral health disparities in vulnerable children. Some of the innovative strategies include the use of interactive parent text-messaging, social networks and financial incentives.
- **Generating Smiles:** Tremendous advances in the development of new tooth-colored materials are restoring and replacing tooth structure lost to dental disease. These discoveries are providing the opportunity for millions of Americans to again smile with comfort and confidence, greatly affecting their emotional well-being, as well as their ability to chew and speak.

From a patient perspective, the research at NIDCR has impacted millions of patients with a wide range of conditions that impede quality of life, are physically debilitating, and create a major financial and social burden. Many complex systemic diseases, ranging from TMJ to autoimmune disorders, such as Behcet's, and to ectodermal dysplasias, have a major oral component. Through research into the basic science that is clearly needed to better understand these diseases; through the discovery of biomarkers for better diagnosis and clinical care; and by the development of new and improved tools for management and treatment, NIDCR has provided hope for these patients and their families that their lives will one day be improved substantially.

An example of an area in which NIDCR is making huge gains is in the understanding of Sjögren's syndrome, a systemic autoimmune disease that affects about four million Americans. In addition to affecting the entire body and causing symptoms of extensive dryness, serious complications can include profound fatigue, chronic pain, major organ involvement, neuropathies and lymphomas. No therapies have been approved for the systemic complications of Sjögren's, but this is changing because NIDCR recently funded a major international registry for Sjögren's that is currently providing researchers with critical data and biospecimens that are being and will continue to be used by many researchers to expand our knowledge. The registry also is an example of how initial NIDCR funding can lead to a major ripple effect in increased research

across the country, because new information increases interest in a disease, facilitates fertilization of ideas across diseases and provides a basis upon which researchers in many specialty areas can build. Clinical practice guidelines are currently being developed for many of these conditions for the first time and are pointing out the vast gaps in our knowledge about the lack of treatment for specific symptoms, which treatments are most effective, the order in which available treatments should be initiated and identifying which patients will benefit most from a specific treatment. NIDCR is leading the cause by proposing funding that would address the important questions raised and the gaps in knowledge. Only with sufficient funding can we build on the incredible advances being made in science and medicine and find answers for the problems affecting millions of desperate patients.

We recognize the fiscal realities and that the overall amount of funding for non-defense discretionary programs is essentially level with the previous year, providing little opportunity for growth. However, the nation's investment in overall discretionary spending is still inadequate to meet the most pressing needs of our country, and we encourage Congress to work together to develop a long-term solution to our debt and deficit that does not rely on cuts to these critical non-defense discretionary spending initiatives like oral health.

Congress has been asked to provide mandatory funding to NIH to help get it through this period of austerity. It is vitally important that no matter how NIH receives additional funding, that Congress honor the long-standing tradition of allocating resources equitably across the entire biomedical research enterprise at NIH including all of the Institutes and Centers. For it is important to note that a discovery in one area of research may benefit another. Maintaining flexibility, honoring the scientific peer-review process and supporting *all* research is critical to our endeavor to bring much needed cures to tens of millions of Americans.

In addition to the NIH, our members care deeply about the Title VII Health Resources and Services Administration (HRSA) programs training the dental health workforce, the Centers for Disease Control and Prevention (CDC) Division of Oral Health's public health prevention efforts, data from the National Center for Health Statistics (NCHS) and the Agency for Healthcare Research & Quality (AHRQ). Please support our funding recommendations for these agencies depicted in the chart below.

Agency	FY12	FY14	FY16	FY17 PBR	FY17 AADR
NIH	**$30.7b**	**$29.9b**	**$32.3b**	**$33.1b**	**$34.5b**
NIDCR	**$410m**	**$398m**	**$413m**	**$413m**	**$452m**
NIMHD	$268m	$271m	$281m	$281m	$302m
AHRQ	$405m	$371m	$334m	$364m	$364m
CDC, Oral Health	$15m	$16m	$18m	$18m	$19m
CDC, NCHS	$154m	$155m	$160m	$160m	$170m
HRSA, Title VII Oral Health	$32m	$32m	$35.8m	$35.8m	$35.8m

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

Diane Coleman

Pesident/CEO

Not Dead Yet

I am writing to support the National Council on Independent Living's request for Congress to reaffirm your commitment to the more than 57 million Americans disabilities by increasing funding in the HHS appropriations for Centers for Independent Living (CILs). I am asking that you increase funding by $200 million, for a total of $301 million for the Independent Living line item in FY 2017.

CILs are cross-disability, non-residential, community-based, nonprofit organizations that are designed and operated by individuals with disabilities. CILs are unique in that they are directly governed and staffed by people with all types of disabilities, including people with mental, physical, sensory, cognitive, and developmental disabilities. Each of the 365 federally funded centers provides five core services: information and referral, individual and systems advocacy, peer support, independent living skills training, and transition services, which were added with the passage of the Workforce Innovation and Opportunity Act (WIOA). From 2012-2014, CILs provided the core services to nearly 5 million people with disabilities, and provided additional services such as housing assistance, transportation, personal care attendants, and employment services to hundreds of thousands of individuals. During this same period, prior to transition being added as a core service, CILs transitioned 13,030 people with disabilities from nursing homes and other institutions into the community.

Transition services were added as a fifth core service with the 2014 reauthorization of the Rehabilitation Act within the Workforce Innovation and Opportunity Act. Transition services include the transition of individuals with significant disabilities from nursing homes and other institutions to home and community-based residences with appropriate supports and services, assistance to individuals with significant disabilities at risk of entering institutions to remain in the community, and the transition of youth with significant disabilities to postsecondary life. This core service is vital to achieving full participation for people with disabilities.

Every day, CILs are fighting to ensure that people with disabilities gain and maintain control over our own lives. We know that this cannot occur when people reside in institutional settings. Opponents of deinstitutionalization say that allowing people with disabilities to live in the community will result in harm. We know that the 13,030 people with disabilities who CILs successfully transitioned out of nursing homes and institutions from 2012-2014 prove otherwise. Additionally, when services are delivered in an individual's home, the result is a tremendous cost savings to Medicaid, Medicare, and states. Community-based services enable people with disabilities to become less reliant on long-term government supports, and they are significantly less expensive than nursing home placements. We are grateful that Congress demonstrated their understanding and support for community-based services when WIOA was passed and transition was added as a fifth core service.

Since transition services were added as a core service, the need for funding is critical. Moreover, CILs need additional funding to restore the devastating cuts to the Independent Living program, make up for inflation costs, and address the increased demand for independent living services. In

2016, the Independent Living Program is receiving $2.5 million less in funding than it was in 2010. It is simply not possible to meet the increasing demand for services and effectively provide transition services without additional funding. Increased funding should be reinvested from the billions currently spent to keep people with disabilities in costly Medicaid nursing homes and institutions and out of mainstream society.

Centers for Independent Living play a crucial role in the lives of people with disabilities, and work tirelessly to ensure that people with disabilities have a real choice in where and how they live, work, and participate in the community. Additionally, CILs are an excellent service and a bargain for America, keeping people engaged with their communities and saving taxpayer money. NCIL is dedicated to increasing the availability of the invaluable and extremely cost-effective services CILs provide, and they have submitted written testimony with a similar request. I strongly support NCIL's testimony.

Kelli Brooks

Executive Director

Lake County Center for Independent Living (serving Lake and McHenry Counties in Illinois)

I am writing to support the National Council on Independent Living's request for Congress to reaffirm your commitment to the more than 57 million Americans disabilities by increasing funding in the HHS appropriations for Centers for Independent Living (CILs). I am asking that you increase funding by $200 million, for a total of $301 million for the Independent Living line item in FY 2017.

CILs are cross-disability, non-residential, community-based, nonprofit organizations that are designed and operated by individuals with disabilities. CILs are unique in that they are directly governed and staffed by people with all types of disabilities, including people with mental, physical, sensory, cognitive, and developmental disabilities. Each of the 365 federally funded centers provides five core services: information and referral, individual and systems advocacy, peer support, independent living skills training, and transition services, which were added with the passage of the Workforce Innovation and Opportunity Act (WIOA). From 2012-2014, CILs provided the core services to nearly 5 million people with disabilities, and provided additional services such as housing assistance, transportation, personal care attendants, and employment services to hundreds of thousands of individuals. During this same period, prior to transition being added as a core service, CILs transitioned 13,030 people with disabilities from nursing homes and other institutions into the community.

Transition services were added as a fifth core service with the 2014 reauthorization of the Rehabilitation Act within the Workforce Innovation and Opportunity Act. Transition services include the transition of individuals with significant disabilities from nursing homes and other institutions to home and community-based residences with appropriate supports and services, assistance to individuals with significant disabilities at risk of entering institutions to remain in the community, and the transition of youth with significant disabilities to postsecondary life. This core service is vital to achieving full participation for people with disabilities.

Every day, CILs are fighting to ensure that people with disabilities gain and maintain control over our own lives. We know that this cannot occur when people reside in institutional settings. Opponents of deinstitutionalization say that allowing people with disabilities to live in the community will result in harm. We know that the 13,030 people with disabilities who CILs successfully transitioned out of nursing homes and institutions from 2012-2014 prove otherwise. Additionally, when services are delivered in an individual's home, **the result is a tremendous cost savings to Medicaid, Medicare, and states.** Community-based services enable people with disabilities to become less reliant on long-term government supports, and they are significantly less expensive than nursing home placements. We are grateful that Congress demonstrated their understanding and support for community-based services when WIOA was passed and transition was added as a fifth core service.

Since transition services were added as a core service, the need for funding is critical. Moreover, CILs need additional funding to restore the devastating cuts to the Independent Living program, make up for inflation costs, and address the increased demand for independent living services. In

2016, the Independent Living Program is receiving $2.5 million less in funding than it was in 2010. It is simply not possible to meet the increasing demand for services and effectively provide transition services without additional funding. Increased funding should be reinvested from the billions currently spent to keep people with disabilities in costly Medicaid nursing homes and institutions and out of mainstream society.

Centers for Independent Living play a crucial role in the lives of people with disabilities, and work tirelessly to ensure that people with disabilities have a real choice in where and how they live, work, and participate in the community. Additionally, CILs are an excellent service and a bargain for America, keeping people engaged with their communities and saving taxpayer money. NCIL is dedicated to increasing the availability of the invaluable and extremely cost-effective services CILs provide, and they have submitted written testimony with a similar request. I strongly support NCIL's testimony.

Jenny Farley

Youth Leadership Advocate

Lake County Center for Independent Living

I am writing to support the National Council on Independent Living's request for Congress to reaffirm your commitment to the more than 57 million Americans disabilities by increasing funding in the HHS appropriations for Centers for Independent Living (CILs). I am asking that you increase funding by $200 million, for a total of $301 million for the Independent Living line item in FY 2017.

CILs are cross-disability, non-residential, community-based, nonprofit organizations that are designed and operated by individuals with disabilities. CILs are unique in that they are directly governed and staffed by people with all types of disabilities, including people with mental, physical, sensory, cognitive, and developmental disabilities. Each of the 365 federally funded centers provides five core services: information and referral, individual and systems advocacy, peer support, independent living skills training, and transition services, which were added with the passage of the Workforce Innovation and Opportunity Act (WIOA). From 2012-2014, CILs provided the core services to nearly 5 million people with disabilities, and provided additional services such as housing assistance, transportation, personal care attendants, and employment services to hundreds of thousands of individuals. During this same period, prior to transition being added as a core service, CILs transitioned 13,030 people with disabilities from nursing homes and other institutions into the community.

Transition services were added as a fifth core service with the 2014 reauthorization of the Rehabilitation Act within the Workforce Innovation and Opportunity Act. Transition services include the transition of individuals with significant disabilities from nursing homes and other institutions to home and community-based residences with appropriate supports and services, assistance to individuals with significant disabilities at risk of entering institutions to remain in the community, and the transition of youth with significant disabilities to postsecondary life. This core service is vital to achieving full participation for people with disabilities.

Every day, CILs are fighting to ensure that people with disabilities gain and maintain control over our own lives. We know that this cannot occur when people reside in institutional settings. Opponents of deinstitutionalization say that allowing people with disabilities to live in the community will result in harm. We know that the 13,030 people with disabilities who CILs successfully transitioned out of nursing homes and institutions from 2012-2014 prove otherwise. Additionally, when services are delivered in an individual's home, the result is a tremendous cost savings to Medicaid, Medicare, and states. Community-based services enable people with disabilities to become less reliant on long-term government supports, and they are significantly less expensive than nursing home placements. We are grateful that Congress demonstrated their understanding and support for community-based services when WIOA was passed and transition was added as a fifth core service.

Since transition services were added as a core service, the need for funding is critical. Moreover, CILs need additional funding to restore the devastating cuts to the Independent Living program, make up for inflation costs, and address the increased demand for independent living services. In

2016, the Independent Living Program is receiving $2.5 million less in funding than it was in 2010. It is simply not possible to meet the increasing demand for services and effectively provide transition services without additional funding. Increased funding should be reinvested from the billions currently spent to keep people with disabilities in costly Medicaid nursing homes and institutions and out of mainstream society.

Centers for Independent Living play a crucial role in the lives of people with disabilities, and work tirelessly to ensure that people with disabilities have a real choice in where and how they live, work, and participate in the community. Additionally, CILs are an excellent service and a bargain for America, keeping people engaged with their communities and saving taxpayer money. NCIL is dedicated to increasing the availability of the invaluable and extremely cost-effective services CILs provide, and they have submitted written testimony with a similar request. I strongly support NCIL's testimony.

Laren C Smith

Home Care Supervisor

SIILC Home Care Services

I am writing to support the National Council on Independent Living's request for Congress to reaffirm your commitment to the more than 57 million Americans disabilities by increasing funding in the HHS appropriations for Centers for Independent Living (CILs). I am asking that you increase funding by $200 million, for a total of $301 million for the Independent Living line item in FY 2017.

CILs are cross-disability, non-residential, community-based, nonprofit organizations that are designed and operated by individuals with disabilities. CILs are unique in that they are directly governed and staffed by people with all types of disabilities, including people with mental, physical, sensory, cognitive, and developmental disabilities. Each of the 365 federally funded centers provides five core services: information and referral, individual and systems advocacy, peer support, independent living skills training, and transition services, which were added with the passage of the Workforce Innovation and Opportunity Act (WIOA). From 2012-2014, CILs provided the core services to nearly 5 million people with disabilities, and provided additional services such as housing assistance, transportation, personal care attendants, and employment services to hundreds of thousands of individuals. During this same period, prior to transition being added as a core service, CILs transitioned 13,030 people with disabilities from nursing homes and other institutions into the community.

Transition services were added as a fifth core service with the 2014 reauthorization of the Rehabilitation Act within the Workforce Innovation and Opportunity Act. Transition services include the transition of individuals with significant disabilities from nursing homes and other institutions to home and community-based residences with appropriate supports and services, assistance to individuals with significant disabilities at risk of entering institutions to remain in the community, and the transition of youth with significant disabilities to postsecondary life. This core service is vital to achieving full participation for people with disabilities.

Every day, CILs are fighting to ensure that people with disabilities gain and maintain control over our own lives. We know that this cannot occur when people reside in institutional settings. Opponents of deinstitutionalization say that allowing people with disabilities to live in the community will result in harm. We know that the 13,030 people with disabilities who CILs successfully transitioned out of nursing homes and institutions from 2012-2014 prove otherwise. Additionally, when services are delivered in an individual's home, the result is a tremendous cost savings to Medicaid, Medicare, and states. Community-based services enable people with disabilities to become less reliant on long-term government supports, and they are significantly less expensive than nursing home placements. We are grateful that Congress demonstrated their understanding and support for community-based services when WIOA was passed and transition was added as a fifth core service.

Since transition services were added as a core service, the need for funding is critical. Moreover, CILs need additional funding to restore the devastating cuts to the Independent Living program, make up for inflation costs, and address the increased demand for independent living services. In

2016, the Independent Living Program is receiving $2.5 million less in funding than it was in 2010. It is simply not possible to meet the increasing demand for services and effectively provide transition services without additional funding. Increased funding should be reinvested from the billions currently spent to keep people with disabilities in costly Medicaid nursing homes and institutions and out of mainstream society.

Centers for Independent Living play a crucial role in the lives of people with disabilities, and work tirelessly to ensure that people with disabilities have a real choice in where and how they live, work, and participate in the community. Additionally, CILs are an excellent service and a bargain for America, keeping people engaged with their communities and saving taxpayer money. NCIL is dedicated to increasing the availability of the invaluable and extremely cost-effective services CILs provide, and they have submitted written testimony with a similar request. I strongly support NCIL's testimony.

Sincerely,

Laren C Smith

Testimony Prepared by Sue Daugherty, RD, LDN - CEO, Metropolitan Area Neighborhood Nutrition Alliance (MANNA) for the United State House Committee on Labor, Health and Human Services, and Education, and Related Agencies addressed to the Department of Health and Human Services

April 15, 2015

MANNA is part of a nationwide coalition, the Food is Medicine Coalition, of over 80 food and nutrition services providers, affiliates and their supporters across the country that provide food and nutrition services to people living with HIV/AIDS (PWH) and other chronic illnesses. In our service area, encompassing the Greater Philadelphia and Southern New Jersey region, we provide nearly 1 million medically tailored, home delivered meals annually. Over 18,000 people have benefited from the 12 million meals that MANNA has delivered over our 26 year history. Collectively, the Food is Medicine Coalition is committed to increasing awareness of the essential role that food and nutrition services (FNS) play in successfully treating HIV/AIDS and to expanding access to this indispensable intervention for people living with other severe illnesses.

1.) Why Food and Nutrition Services (FNS) Matter for PWH

While adequate food and nutrition are basic to maintaining health for all persons, good nutrition is crucial for the management of HIV infection. Proper nutrition is needed to increase absorption of medication, reduce side effects, and maintain healthy body weight. Research has identified the virus as an independent risk factor for cardiovascular, liver and kidney disease, cancer, osteoporosis and stroke. Several HIV medications can cause nausea and vomiting and some can affect lab results that test lipids and kidney and liver function. These compounding health effects, caused by the virus and its medications, reinforce the important role a nutrient-rich diet plays in a patient's overall care plan. In addition, providing food and nutrition services can serve to facilitate access and engagement with medical care, especially among vulnerable populations.

The Food and Nutrition Services category within the Ryan White Program includes medical nutritional therapy (MNT) and food and nutrition services (FNS). MNT covers nutritional diagnostic, therapy, and counseling services focused on prevention, delay or management of diseases and conditions, and involves an in-depth assessment, periodic reassessment and intervention provided by a licensed, Registered Dietitian Nutritionist (RDN) outside of a primary care visit. The range of FNS provided through the Ryan White program complements the needs of PWH at any stage of their illness. For those who are most mobile, there are congregate meals, walk-in food pantries and voucher programs. For those whose disease has progressed, home-delivered meals and home-delivered grocery bags complement their medical treatment.

Since 2006, HRSA has included MNT and FNS, provided under the guidance of RDNs, as a clinically effective **core medical service** in the Ryan White Program. These services play a critical role in ensuring that PWH enter and continue in primary medical care, adhere to their medications, and ultimately achieve viral suppression.

2.) FNS as a Care Completion Service Unique to Ryan White

Social and economic interventions, most often in the form of care completion service like food and nutrition services, are fundamental to making health care work for PWH. Support services for PWH are not covered in any comprehensive way by Medicaid or other public insurance initiatives that have been expanded by the Affordable Care Act. As the HIV epidemic in the United States increasingly impacts low-income individuals, support services help stabilize individuals living with or at risk of HIV. When needs are met, and life's emergencies are held at bay, PWH are poised to remain connected to care and treatment.

3.) Access to FNS and the Triple Aim

Access to appropriate food and nutrition services (FNS) are increasingly recognized as key to accomplishing the triple aim of national healthcare reform for PWH.

Better Health Outcomes

When clients get effective FNS and become food secure, they then keep scheduled primary care visits, score higher on health functioning, are at lower risk for inpatient hospital stays and are more likely to take their medicines[i]. Studies show both the health benefits of access to MNT and/or nutrition counseling for people with HIV infections[ii] and the resulting decreases in their healthcare costs. Compare these outcomes to PWH who are food insecure, who have:

- Lower CD4 counts & lower likelihoods of having undetectable viral loads[iii]
- More ER visits[iv] & increased morbidity and mortality[v]
- More missed primary care appointments & reduced use of antiretroviral therapy[vi].

Lower Healthcare Costs

Millions of dollars in healthcare expenditures are saved through the provision of FNS to PWH. A recent study comparing participants in a medically-tailored FNS program vs. a control group within a local managed care organization found that average monthly healthcare costs for PWH fell 80% in first three months after receiving FNS[vii]. If hospitalized, nourished clients' costs were 30% lower, their hospital length of stay was cut by 37% and they were 20% more likely to be able to be discharged to their homes rather than a more expensive institution[viii]. Furthermore, FNS are a very inexpensive intervention. For each day in a hospital saved, you can feed a person a medically-tailored diet for half a year.

Improved Patient Satisfaction

Studies show nutrition counseling improves quality of life[ix]. Members overwhelmingly report that our services help them live more independently, eat more nutritiously and manage their medical treatment more effectively.

4.) FNS and the National HIV/AIDS Strategy (NHAS)

Access to FNS for PWH is fundamental to fulfilling the goals of the NHAS.

- **NHAS Goal: Reducing new HIV infections:** PWH who are food insecure are less likely to have undetectable viral loads in a statistically significant way. Undetectable viral loads prevent transmission 96% of the time[x], thus, FNS is key to prevention[xi].
- **NHAS Goal: Increasing access to care and improving health outcomes for people living with HIV:** PWH who receive effective FNS are more likely to keep scheduled primary care visits, score higher on health functioning, are at lower risk for inpatient hospital stays and are more likely to take their medicines[xii].
- **NHAS Goal: Reducing HIV-related disparities and health inequities:** By providing FNS to PWH who are in need largely because of poverty, we improve health outcomes, thereby reducing health disparities[xiii].
- **NHAS Goal: Achieving a more coordinated national response to the HIV epidemic:** There remains a tremendous variation by state in coverage of food and nutrition services both inside and outside of Ryan White, making support for Ryan White HIV Program all the more needed. Ultimately, if we are going to achieve a more coordinated national response to the HIV epidemic and our quest to reduce healthcare spending nationwide, FNS must be included in all healthcare reform efforts, including Ryan White and the ACA.

Conclusion

We are deeply aware of the difficult decisions that face the members of the Committee in the current fiscal environment. Yet, research shows that investment in FNS, with the great return in prevention and retention in HIV care, are vital to lowering the number of new infections in the domestic HIV epidemic and ultimately reducing healthcare costs and preserving healthcare resources for the future. A client's diet can literally have life and death consequences. When people are severely ill, good nutrition is one of the first things to deteriorate, making recovery and stabilization that much harder, if not impossible. Early and reliable access to medically-appropriate FNS helps PWH live healthy and productive lives, produces better overall health outcomes and reduces health care costs.

Along with our colleagues, we appreciate the opportunity to offer this testimony regarding the FY 2017 Appropriations process. We are also pleased to offer our assistance and expertise, including information from our Research Library.

Thank you.

Sue Daugherty, RD, LDN
Chief Executive Officer
Metropolitan Area Neighborhood Nutrition Alliance (MANNA)
2323 Ranstead St
Philadelphia, PA 19103
215-496-2662 x101
sdaugherty@mannapa.org

---

[i] Aidala A, Yomogida M, Vardy Y & the Food & Nutrition Study Team. Food and Nutrition Services, HIV Medical Care, and Health Outcomes. New York State Department of Health: Resources for Ending the Epidemic,

2014. Available at https://www.health.ny.gov/diseases/aids/ending_the_epidemic/docs/key_resources/housing_and_supportive_services/chain_factsheet3.pdf

[ii] Academy of Nutrition and Dietetics (formerly American Dietetic Association). HIV/AIDS Nutrition Evidence Analysis Project at http://www.adaevidencelibrary.com/conclusion.cfm?conclusion_statement_id=250707 Accessed 29 July 2012.

[iii] Aidala A., Yomogida M., and the HIV Food & Nutrition Study Team (2011);
Singe AW,Weiser SD, McCoy, SI. Does Food Insecurity Undermine Adherence to Antiretroviral Therapy? A Systematic Review. AIDS Behav (2015) 19:1510–1526.

[iv] Ibid.

[v] Anema A, Chan K, Yip B, Weiser S, Montaner JSG, Hogg RS. Impact of food insecurity on survival among HIV-positive injection drug users receiving antiretroviral therapy in a Canadian cohort. 141st APHA Annual Meeting, Nov. 2-6, 2013. Boston, MA. Abstract #: 290277

[vi] Aidala A., Yomogida M., and the HIV Food & Nutrition Study Team (2011).

[vii] Gurvey J, Rand K, Daugherty S, Dinger C, Schmeling J, Laverty N. Examining Health Care Costs Among MANNA Clients and a Comparison Group. J Prim Care Community Health. (2013) 4:311-317

[viii]Ibid.

[ix] Rabeneck L, Palmer A, Knowles JB, Seidehamel RJ, Harris CL, Merkel KL, Risser JMH, Akrabawi SS. A randomized controlled trial evaluating nutrition counseling with or without oral supplementation in malnourished HIV-infected patients. J Am Diet Assoc. (1998) 98: 434-438;Schwenk A, Steuck H, Kremer G. Oral supplements as adjunctive treatment to nutritional counseling in malnourished HIV-infected patients: randomized controlled trial. Clinical Nutrition (1999) 18(6): 371-374.

[x] M. S. Cohen *et al.*, Prevention of HIV-1 Infection with Early Antiretroviral Therapy. N. Engl. J. Med.(2011) 365, 493-505 . HPTN 052

[xi] Palar K, Laraia B, Tsai A, Weiser SD Food insecurity is associated with sexually transmitted infections and HIV serostatus among low income adults in the National Health and Nutrition Examination Survey (NHANES) (1999-2010). Presented at the American Public Health Association 141st Annual Meeting, Boston, MA, November 5, 2013.

[xii] Aidala A, Yomogida M, Vardy Y & the Food & Nutrition Study Team. Food and Nutrition Services, HIV Medical Care, and Health Outcomes. New York State Department of Health: Resources for Ending the Epidemic, 2014. Available at

xiii Weiser SD, Frongillo EA, Ragland K, Hogg RS, Riley ED, Bangsberg DR. Food insecurity is associated with incomplete HIV RNA suppression among homeless and marginally housed HIV-infected individuals in San Francisco. J Gen Intern Med. (2009) 24(1):14-20.

3 Park Place, Suite 307
Annapolis, MD 21401-3722 USA

Phone: 301-731-4535
Fax: 301-731-4538

esa@entsoc.org
www.entsoc.org

Testimony of
May Berenbaum, PhD, President
Entomological Society of America
On
Fiscal Year 2017 Appropriations for the National Institutes of Health and Centers for Disease Control and Prevention
Submitted to the
Appropriations Subcommittee on Labor, Health and Human Services, Education, and Related Agencies
United States House of Representatives

April 15, 2016

The Entomological Society of America (ESA) respectfully submits this statement for the official record in support of funding for arthropod-borne disease research at the U.S. Department of Health and Human Services (HHS). **ESA requests a robust fiscal year (FY) 2017 appropriation for the National Institutes of Health (NIH), including funding equal to FY 2016 enacted levels for arthropod-borne disease research at the National Institute of Allergy and Infectious Diseases (NIAID). The Society also supports the President's increased investment in the core infectious diseases budget and the global health budget within the Centers for Disease Control and Prevention (CDC) in order to fund scientific activities related to vector-borne diseases.**

Cutting-edge research in the biological sciences, including the field of entomology, is essential for addressing societal needs related to environmental and human health. Many species of insects and their arachnid relatives (including ticks and mites) serve as vectors of a diversity of infectious diseases that threaten the health and well-being of people across the globe, including populations in every state and territory of the United States and U.S. military personnel serving abroad. Vector-borne diseases can be particularly challenging to control; effective vaccines are not available for many of these diseases, and controlling the vectors is complicated by their mobility and their propensity for developing pesticide resistance. The risk of emerging infectious diseases grows as global travel increases in speed and frequency and as environmental conditions conducive to vector population growth continue to expand globally. The exponential rise of the Zika virus in the Americas is an example of the astonishing rapidity with which an insect-borne disease can become pandemic. Entomological research aimed at elucidating the relationships between arthropod vectors and the diseases they transmit–including, in the case of mosquitoes, dengue, Zika virus, and chikungunya, and, in the case of ticks, Lyme disease, human anaplasmosis and ehrlichiosis –is essential for reliable monitoring and prediction of outbreaks, effective prevention of disease transmission, and rapid diagnosis and treatment of diseases. The magnitude of the challenges presented by vector-borne diseases cannot be overstated; mosquitoes alone are considered responsible for the deaths of more people than all other animal species together (including humans). **Given the enormous impact of arthropod vectors on human health, ESA urges the subcommittee to support vector-borne disease research**

programs that incorporate the entomological sciences as part of a comprehensive approach to addressing infectious diseases.

NIH, the nation's premier medical research agency, advances human health by support of research on basic human and pathogen biology and by development of prevention and treatment strategies. More than 80 percent of NIH funding is competitively awarded to scientists at approximately 2,500 universities, medical schools, and other research institutions across the nation. As one of NIH's 27 institutes and centers, NIAID conducts and supports fundamental and applied research related to the understanding, prevention, and treatment of infectious, immunologic, and allergic diseases. One example of NIAID-funded research on infectious diseases is a study examining the mechanism by which DEET, a widely used synthetic mosquito repellent discovered more than 60 years ago, is perceived by the southern house mosquito, a vector of St. Louis encephalitis and West Nile virus. DEET was shown to bind to and activate a specific odorant receptor on the antennae of female mosquitoes; moreover, inactivating the gene that codes for the receptor protein dramatically reduced the repellency of DEET. These investigators also showed that methyl jasmonate, a plant-derived mosquito repellent, activates the same receptor, opening up the possibility that this specific odorant receptor may be a useful target for developing new, safe and affordable repellents.[1] Another example of infectious disease research supported by NIAID is an ongoing study aimed at understanding the molecular mechanisms underlying the feeding behavior of the black-legged tick and the lone star tick; these two species are principal vectors for multiple human tick-borne diseases in the United States, including Lyme disease. These ticks, which must feed for several days, remain attached to their hosts by producing an adhesive secretion known as tick cement. In this study, investigators are working to identify the proteins in tick cement that are injected first into the feeding site, before transmission of disease-causing pathogens, including the Lyme disease agent. Identifying these proteins and disabling them can provide an entirely new strategy for disrupting the transmission cycle of Lyme disease and other tick-borne human illnesses.[2] **To ensure funding for future groundbreaking projects of great utility for public health, ESA supports increased funding for NIAID and encourages the committee to support vector-borne disease research at NIH. In particular, ESA supports funding equal to the FY 2016 enacted level of $1.375 billion for Biodefense and Emerging Infectious Diseases.**

CDC, serving as the nation's leading health protection agency, conducts science and provides health information to prevent and respond to infectious diseases and other global health threats, irrespective of whether they arise naturally or via acts of bioterrorism. Within the core infectious diseases budget of CDC, the Division of Vector-Borne Diseases (DVBD) aims to protect the nation from the threat of viruses and bacteria transmitted primarily by mosquitoes, ticks, and fleas. DVBD's mission is carried out by a staff of experts in several scientific disciplines, including entomology. For example, among the activities supported by DVBD are the ArboNET surveillance system for mosquito-borne diseases and the TickNET system for tick-borne

---

[1] Xu, P et al. 2014. Mosquito odorant receptor for DEET and methyl jasmonate. Proc. Natl. Acad. Sci. USA 111: 16593-16597 (NIAID NIH Award R01AI095514).

[2] Mulenga, A. 2016. *Ixodes scapularis* and *Ambylomma americanum* tick cement proteome. (NIAID NIH Award 1R21AI119873-01A1

diseases. ArboNET is a nationwide network managed by CDC and state health departments that monitors West Nile virus, Zika virus and other arthropod-borne diseases through a variety of activities, including the collection and testing of mosquitoes. TickNET is a partnership between state and local health departments and the CDC's Division of Vector-Borne Diseases and Division of Parasitic diseases that tracks tick-borne diseases such as Lyme disease and funds applied research aimed at prevention and pathogen discovery. As well, a component of CDC's global health budget supports activities on malaria and other parasitic diseases, which include maintaining a global reference insectary that houses colonies of mosquitoes from around the world to be used by the agency for studies on malaria transmission.

Specifically, within the President's FY 2017 Budget Request for CDC, there was a proposed increase of $34.6 million for Core Infectious Diseases over the FY 2016 enacted level, which includes the vector-borne diseases program. The CDC FY 2017 budget justification also highlights the Zika virus, along with several other vector-borne diseases, including dengue, chikungunya, West Nile virus, and Lyme disease, as program priorities. ESA applauds the identification of vector-borne diseases as a FY 2017 priority for CDC and encourages the inclusion of entomological sciences in future research addressing these diseases. **Given that the contributions of the CDC are vital for the health security of the nation, ESA requests that the committee provide the President's requested increased support for CDC programs addressing vector-borne diseases.**

ESA, headquartered in Annapolis, Maryland, is the largest organization in the world serving the professional and scientific needs of entomologists and individuals in related disciplines. Founded in 1889, ESA has nearly 7,000 members affiliated with educational institutions, health agencies, private industry, and government. Members are researchers, teachers, extension service personnel, administrators, marketing representatives, research technicians, consultants, students, pest management professionals, and hobbyists.

Thank you for the opportunity to offer the Entomological Society of America's support for HHS research programs. For more information about the Entomological Society of America, please see http://www.entsoc.org/.

Name Fiona Hinze

Title Systems Change Coordinator/Community Organizer

Institutional Affiliation Independent Living Resource Center San Francisco

I am writing on behalf of Independent Living Resource Center San Francisco (ILRCSF) to support the National Council on Independent Living's request for Congress to reaffirm your commitment to the more than 57 million Americans with disabilities by increasing funding in the HHS appropriations for Centers for Independent Living (CILs). We are asking that you increase funding by $200 million, for a total of $301 million for the Independent Living line item in FY 2017.

CILs are cross-disability, non-residential, community-based, nonprofit organizations that are designed and operated by individuals with disabilities. CILs are unique in that they are directly governed and staffed by people with all types of disabilities, including people with mental, physical, sensory, cognitive, and developmental disabilities. Each of the 365 federally funded centers provides five core services: information and referral, individual and systems advocacy, peer support, independent living skills training, and transition services, which were added with the passage of the Workforce Innovation and Opportunity Act (WIOA). From 2012-2014, CILs provided these core services to nearly 5 million people with disabilities, and provided additional services such as housing assistance, transportation, personal care attendants, and employment services to hundreds of thousands of individuals. During this same period, prior to transition being added as a core service, CILs transitioned 13,030 people with disabilities from nursing homes and other institutions into the community.

Transition services were added as a fifth core service with the 2014 reauthorization of the Rehabilitation Act within the Workforce Innovation and Opportunity Act. Transition services include the transition of individuals with significant disabilities from nursing homes and other institutions to home and community-based residences with appropriate supports and services, assistance to individuals with significant disabilities at risk of entering institutions to remain in the community, and the transition of youth with significant disabilities to postsecondary life. This core service is vital to achieving full participation for people with disabilities.

Every day, CILs are fighting to ensure that people with disabilities gain and maintain control over our own lives. We know that this cannot occur when people reside in institutional settings. Opponents of deinstitutionalization say that allowing people with disabilities to live in the community will result in harm. We know that the 13,030 people with disabilities who CILs successfully transitioned out of nursing homes and institutions from 2012-2014 prove otherwise. Additionally, when services are delivered in an individual's home, the result is a tremendous cost savings to Medicaid, Medicare, and states. Community-based services enable people with disabilities to become less reliant on long-term government supports, and they are significantly less expensive than nursing home placements. We are grateful that Congress demonstrated their understanding and support for community-based services when WIOA was passed and transition was added as a fifth core service.

Since transition services were added as a core service, the need for funding is critical. Moreover, CILs need additional funding to restore the devastating cuts to the Independent Living program,

make up for inflation costs, and address the increased demand for independent living services. In 2016, the Independent Living Program is receiving $2.5 million less in funding than it was in 2010. It is simply not possible to meet the increasing demand for services and effectively provide transition services without additional funding. Increased funding should be reinvested from the billions currently spent to keep people with disabilities in costly Medicaid nursing homes and institutions and out of mainstream society.

Centers for Independent Living play a crucial role in the lives of people with disabilities, and work tirelessly to ensure that people with disabilities have a real choice in where and how they live, work, and participate in the community. Additionally, CILs are an excellent service and a bargain for America, keeping people engaged with their communities and saving taxpayer money. NCIL is dedicated to increasing the availability of the invaluable and extremely cost-effective services CILs provide, and they have submitted written testimony with a similar request. HLRCSF strongly supports NCIL's testimony.

Ryan White Medical Providers Coalition

Record Testimony for the U.S. House Appropriations Subcommittee on Labor, Health and Human Services, Education, and Related Agencies

Submitted by Alice Thornton, MD
University of Kentucky, Chief Infectious Diseases;
Medical Director, Bluegrass Care Clinic, Lexington, Kentucky; and
Co-Chair, Ryan White Medical Providers Coalition

April 13, 2016

My name is Dr. Alice C. Thornton, and I serve as Medical Director of the Bluegrass Care Clinic (BCC) at the University of Kentucky Medical Center in Lexington, Kentucky. I write to submit testimony on behalf of the Ryan White Medical Providers Coalition (RWMPC), which I Co-Chair. RWMPC is a national coalition of medical providers and administrators who work in clinics 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 its $4 million funding increase for Ryan White Part C Programs in FY 16. And while I am very grateful for this support, and understand that times are hard, **I request $225.1 million, or a $20 million increase, for Ryan White Part C programs in FY 17.** While I know that this is a lot of funding, ***it is in fact well below the estimated need – in 2015, my clinic alone enrolled 179 new patients into care – a 14 percent increase in one year.*** These funds help Ryan White clinics identify, engage, and effectively treat persons living with HIV/AIDS in a way that saves both lives and money.

My Ryan White-funded clinic, the BCC, has served as the source for HIV primary care in the 63 counties of central and eastern Kentucky for the past 25 years. Over half of the counties served are federally recognized as economically distressed, and BCC cares for 74% of the people living with HIV in the region. Since the BCC received its first Part C grant in 2001, the number of patients has increased by almost 300%. ***To help fund these enormous patient and cost increases, the University incurs an annual deficit of approximately $1.2 million.***

Most Part C clinics, including BCC, also receive support from other parts of the Ryan White Program (RWP) that help us provide medications; additional medical care, such as dental

services; and support services, such as case management and transportation – all essential components of the effective Ryan White HIV care model that results in excellent outcomes.

Ryan White Part C Programs Support Comprehensive, Expert, and Effective HIV Care

Part C of the Ryan White Program directly funds comprehensive and effective HIV care and treatment – services that are responsible for the dramatic decrease in AIDS-related mortality and morbidity over the last decade. The Ryan White Program has supported the development of expert HIV care and treatment programs that achieve key outcomes that improve individual health and help prevent the transmission of HIV. In 2011, a ground-breaking clinical trial – **named the "scientific breakthrough of the year" by *Science* magazine** – found that HIV treatment not only saves the lives of people living with HIV, **but also reduces HIV transmission risk to near zero – proving that HIV treatment is also HIV prevention.**

The comprehensive, HIV care model that is supported by the Ryan White Program has been highly successful at achieving positive clinical outcomes with a complex patient population.[1] In a convenience sample of eight Ryan White-funded Part C programs ranging from the rural South to the Bronx, ***retention in care rates ranged from 87 to 97 percent***. However, estimates from the Centers for Disease Control and Prevention (CDC) show that only 40 percent of all people with HIV are engaged in care nationally.[2] Once in care, patients served at Ryan White clinics do very well— ***more than 81% of Ryan White patients achieved viral suppression in 2014.*** BCC is doing even better than this national average for Ryan White clinics – ***in 2015, 92% of BCC patients had an undetectable viral load. Additionally, many BCC patients continue to work and remain active community members.***

Investing in Ryan White Part C Programs Saves Both Lives and Money

Early and reliable access to HIV care and treatment both helps patients with HIV live relatively ***healthy and productive lives*** and is more ***cost effective***. One study from the Part C Clinic at the

[1] See *Improvement in the Health of HIV-Infected Persons in Care: Reducing Disparities* at http://cid.oxfordjournals.org/content/early/2012/08/24/cid.cis654.full.pdf+html.
[2] See CDC's *HIV in the United States: The Stages of Care*, http://www.cdc.gov/nchhstp/newsroom/docs/HIV-Stages-of-Care-Factsheet-508.pdf, November 2014.

University of Alabama at Birmingham found that patients treated at the later stages of HIV disease required ***2.6 times more health care dollars*** than those receiving earlier treatment meeting federal HIV treatment guidelines. ***On average it costs $3,501 per person per year to provide the comprehensive outpatient care and treatment available at Part C funded programs.*** The comprehensive services provided often include lab work, STD/TB/Hepatitis screening, ob/gyn care, dental care, mental health and substance abuse treatment, and case management. ***This is a bargain when compared to the high cost of hospital and emergency care.***

Fully Funding and Maintaining Ryan White Part C Programs Is Essential

Because of both the inadequacy of insurance coverage for people with complex conditions such as HIV and the fact that some individuals will remain uncovered, ***fully funding and maintaining the Ryan White Program is essential to providing comprehensive, expert and effective HIV care nationwide.*** However, RWMPC is concerned about the proposal to consolidate Ryan White Part D funding into Part C. RWMPC's specific concerns include:

- ***Parts C and D programs both provide comprehensive, effective care and treatment for women, infants, children and youth living with HIV/AIDS. However, Part D programs have cultivated special expertise for engaging and retaining women (including pregnant women) and young people in care and Part D allows funding for key services not covered by Part C.*** With adolescents accounting for 26% of new HIV infections in the U.S., it is still critical to target resources to support the effective, comprehensive services that Part D programs provide to these vulnerable populations and not enact this significant structural change outside of a broader reauthorization of the program.
- ***In some communities, Part D-funded programs are the main providers of HIV care and treatment.*** It is critical to ensure that implementation of any budget proposal does not leave any community without adequate access to effective and comprehensive HIV care and treatment. Also, for Ryan White medical clinics that currently receive only Part D funding, it could prove difficult to successfully compete for Part C funding if there already is a Part C program serving that community; and loss of that Part D program could reduce the community's overall access to HIV and treatment.

- ***It is unclear exactly how the proposed consolidation would impact grantees***. More detail outlining how the consolidation process would actually impact grantees and access to HIV care and treatment in specific communities is needed before instituting a program change that could reduce community access to HIV care and treatment.

At this critical time in the HIV/AIDS epidemic, when research has confirmed that early access to HIV care and treatment not only saves lives but prevents new infections by reducing the risk of transmission to near zero for patients who are virally suppressed and keeps patients engaged and working, ***it is essential to maintain overall funding levels for the Ryan White Program.*** Increasing access to and successful engagement in effective, comprehensive HIV care and treatment is the only way to lead the nation to an AIDS-free generation and reduce the devastating costs of – including lives lost to – HIV infection.

Continue to Permit the Use of Federal Funds for Syringe Access Programs that Help to Advance Public Health and Address Drug Use in Kentucky and Nationwide

RWMPC commends Congress for leading the nation by modifying the ban on federal funding for syringe access programs. RWMPC is committed to evidence-based public health interventions that both increase access to health care and decrease transmission of HIV, viral hepatitis, and other blood-borne pathogens. Injection drug use is a major transmission route for these infections, and increasing access to syringe access programs through federal funding will help decrease the spread of hepatitis C and HIV, as well as help connect individuals to critical health care and support services, including overdose prevention, substance use treatment, and medical care for hepatitis C, HIV, and other life-threatening infections.

Kentucky has one of the highest rates of acute hepatitis C in the country. We have seen a dramatic increase in hepatitis C infections with a majority of infections occurring in young persons who live in non-urban areas with a history of injection drug use, and previously used opioid agonists such as oxycodone.[i] In University of Kentucky's infectious diseases practice, hepatitis C and infections such as endocarditis, have compromised the lives of too many Kentuckians, and we have been frustrated by our inability to employ the full range of effective tools available to prevent infections and help patients address their addiction. These problems

also have been seen in West Virginia, Ohio, and many other states and communities, including Scott County, Indiana, where new HIV infections reached 168 in just the first six months of 2015 in a small, rural area that beforehand had under 10 HIV infections each year.

Last year, Kentucky legislators acted decisively to improve public health and the lives of residents by passing into law a comprehensive set of medical interventions, including expanded access to opioid overdose medication and substance use treatment. The law also included a syringe exchange program provision that allows local jurisdictions to establish syringe access programs that provide clean syringes and other critical services, including referral to substance use treatment and other needed medical care. My clinic worked with the local public health department to establish the syringe access program in Lexington, and we are pleased that federal funds now could help support the budget of this and other syringe access programs nationwide.

Data from the Centers for Disease Control and Prevention (CDC) highlighting links between HIV infection and injection drug use illustrate the importance of syringe access programs. Data, published in CDC's Morbidity and Mortality Weekly Report, were gathered from 20 U.S. cities in 2012 and showed that of more than 10,000 injecting drug users tested for HIV, 11 percent are infected with HIV. Of those who answered interview questions, 30 percent reported injecting themselves with a syringe that was shared with other people.

We urge Congress to maintain the FY16 omnibus appropriations language that allows access to syringe services in jurisdictions that are experiencing or are at risk for an increase in hepatitis infections or an HIV outbreak due to injection drug use as a key element of infectious disease prevention and as a way to identify and engage individuals in critical medical care, including substance use treatment. **And again, we urge you to please fully fund the Ryan White Program this year.** Thank you so much for your time and consideration of these requests.

---

[1] Centers for Disease Control and Prevention. Surveillance for Viral Hepatitis – United States, 2012. Online at: http://www.cdc.gov/hepatitis/Statistics/2012Surveillance/Commentary.htm.

Delivering hope, one meal at a time

219 RIGGS ROAD NE
WASHINGTON, DC 20011
PHONE (202) 269-2277
WWW.FOODANDFRIENDS.ORG

Testimony Prepared by Craig Shniderman, Executive Director of Food & Friends for the United State House Committee on Labor, Health and Human Services, and Education, and Related Agencies addressed to the Department of Health and Human Services

April 15, 2015

Food & Friends is part of a nationwide coalition, the Food is Medicine Coalition, of over 80 food and nutrition services providers, affiliates and their supporters across the country that provide food and nutrition services to people living with HIV/AIDS (PWH) and other chronic illnesses. In our service area, we provide over 1 million medically tailored, home delivered meals annually. Collectively, the Food is Medicine Coalition is committed to increasing awareness of the essential role that food and nutrition services (FNS) play in successfully treating HIV/AIDS and to expanding access to this indispensable intervention for people living with other severe illnesses.

1.) Why Food and Nutrition Services (FNS) Matter for PWH

While adequate food and nutrition are basic to maintaining health for all persons, good nutrition is crucial for the management of HIV infection. Proper nutrition is needed to increase absorption of medication, reduce side effects, and maintain healthy body weight. Research has identified the virus as an independent risk factor for cardiovascular, liver and kidney disease, cancer, osteoporosis and stroke. Several HIV medications can cause nausea and vomiting and some can affect lab results that test lipids and kidney and liver function. These compounding health effects, caused by the virus and its medications, reinforce the important role a nutrient-rich diet plays in a patient's overall care plan. In addition, providing food and nutrition services can serve to facilitate access and engagement with medical care, especially among vulnerable populations.

The Food and Nutrition Services category within the Ryan White Program includes medical nutritional therapy (MNT) and food and nutrition services (FNS). MNT covers nutritional diagnostic, therapy, and counseling services focused on prevention, delay or management of diseases and conditions, and involves an in-depth assessment, periodic reassessment and intervention provided by a licensed, Registered Dietitian Nutritionist (RDN) outside of a primary care visit. The range of FNS provided through the Ryan White program complements the needs of PWH at any stage of their illness. For those who are most mobile, there are congregate meals, walk-in food pantries and voucher programs. For those whose disease has progressed, home-delivered meals and home-delivered grocery bags complement their medical treatment.

Since 2006, HRSA has included MNT and FNS, provided under the guidance of RDNs, as a clinically effective **core medical service** in the Ryan White Program. These services play a

critical role in ensuring that PWH enter and continue in primary medical care, adhere to their medications, and ultimately achieve viral suppression.

2.) FNS as a Care Completion Service Unique to Ryan White

Social and economic interventions, most often in the form of care completion service like food and nutrition services, are fundamental to making health care work for PWH. Support services for PWH are not covered in any comprehensive way by Medicaid or other public insurance initiatives that have been expanded by the Affordable Care Act. As the HIV epidemic in the United States increasingly impacts low-income individuals, support services help stabilize individuals living with or at risk of HIV. When needs are met, and life's emergencies are held at bay, PWH are poised to remain connected to care and treatment.

3.) Access to FNS and the Triple Aim

Access to appropriate food and nutrition services (FNS) are increasingly recognized as key to accomplishing the triple aim of national healthcare reform for PWH.

Better Health Outcomes

When clients get effective FNS and become food secure, they then keep scheduled primary care visits, score higher on health functioning, are at lower risk for inpatient hospital stays and are more likely to take their medicines[i]. Studies show both the health benefits of access to MNT and/or nutrition counseling for people with HIV infections[ii] and the resulting decreases in their healthcare costs. Compare these outcomes to PWH who are food insecure, who have:

- Lower CD4 counts & lower likelihoods of having undetectable viral loads[iii]
- More ER visits[iv] & increased morbidity and mortality[v]
- More missed primary care appointments & reduced use of antiretroviral therapy[vi].

Lower Healthcare Costs

Millions of dollars in healthcare expenditures are saved through the provision of FNS to PWH. A recent study comparing participants in a medically-tailored FNS program vs. a control group within a local managed care organization found that average monthly healthcare costs for PWH fell 80% in first three months after receiving FNS[vii]. If hospitalized, nourished clients' costs were 30% lower, their hospital length of stay was cut by 37% and they were 20% more likely to be able to be discharged to their homes rather than a more expensive institution[viii]. Furthermore, FNS are a very inexpensive intervention. For each day in a hospital saved, you can feed a person a medically-tailored diet for half a year.

Improved Patient Satisfaction

Studies show nutrition counseling improves quality of life[ix]. Members overwhelmingly report that our services help them live more independently, eat more nutritiously and manage their medical treatment more effectively.

4.) FNS and the National HIV/AIDS Strategy (NHAS)

Access to FNS for PWH is fundamental to fulfilling the goals of the NHAS.

- **NHAS Goal: Reducing new HIV infections:** PWH who are food insecure are less likely to have undetectable viral loads in a statistically significant way. Undetectable viral loads prevent transmission 96% of the time[x], thus, FNS is key to prevention[xi].
- **NHAS Goal: Increasing access to care and improving health outcomes for people living with HIV:** PWH who receive effective FNS are more likely to keep scheduled primary care visits, score higher on health functioning, are at lower risk for inpatient hospital stays and are more likely to take their medicines[xii].
- **NHAS Goal: Reducing HIV-related disparities and health inequities:** By providing FNS to PWH who are in need largely because of poverty, we improve health outcomes, thereby reducing health disparities[xiii].
- **NHAS Goal: Achieving a more coordinated national response to the HIV epidemic:** There remains a tremendous variation by state in coverage of food and nutrition services both inside and outside of Ryan White, making support for Ryan White HIV Program all the more needed. Ultimately, if we are going to achieve a more coordinated national response to the HIV epidemic and our quest to reduce healthcare spending nationwide, FNS must be included in all healthcare reform efforts, including Ryan White and the ACA.

Conclusion

We are deeply aware of the difficult decisions that face the members of the Committee in the current fiscal environment. Yet, research shows that investment in FNS, with the great return in prevention and retention in HIV care, are vital to lowering the number of new infections in the domestic HIV epidemic and ultimately reducing healthcare costs and preserving healthcare resources for the future. A client's diet can literally have life and death consequences. When people are severely ill, good nutrition is one of the first things to deteriorate, making recovery and stabilization that much harder, if not impossible. Early and reliable access to medically-appropriate FNS helps PWH live healthy and productive lives, produces better overall health outcomes and reduces health care costs.

Along with our colleagues, we appreciate the opportunity to offer this testimony regarding the FY 2017 Appropriations process. We are also pleased to offer our assistance and expertise, including information from our Research Library.

Thank you.

Craig Shniderman
Executive Director
Food & Friends
219 Riggs Rd NE
Washington DC 20011
202-269-6839
cshniderman@foodandfriends.org

[i] Aidala A, Yomogida M, Vardy Y & the Food & Nutrition Study Team. Food and Nutrition Services, HIV Medical Care, and Health Outcomes. New York State Department of Health: Resources for Ending the Epidemic,

2014. Available at https://www.health.ny.gov/diseases/aids/ending_the_epidemic/docs/key_resources/housing_and_supportive_services/chain_factsheet3.pdf

[ii] Academy of Nutrition and Dietetics (formerly American Dietetic Association). HIV/AIDS Nutrition Evidence Analysis Project at http://www.adaevidencelibrary.com/conclusion.cfm?conclusion_statement_id=250707 Accessed 29 July 2012.

[iii] Aidala A., Yomogida M., and the HIV Food & Nutrition Study Team (2011);
Singe AW,Weiser SD, McCoy, SI. Does Food Insecurity Undermine Adherence to Antiretroviral Therapy? A Systematic Review. AIDS Behav (2015) 19:1510-1526.

[iv] Ibid.

[v] Anema A, Chan K, Yip B, Weiser S, Montaner JSG, Hogg RS. Impact of food insecurity on survival among HIV-positive injection drug users receiving antiretroviral therapy in a Canadian cohort. 141st APHA Annual Meeting, Nov. 2-6, 2013. Boston, MA. Abstract #: 290277

[vi] Aidala A., Yomogida M., and the HIV Food & Nutrition Study Team (2011).

[vii] Gurvey J, Rand K, Daugherty S, Dinger C, Schmeling J, Laverty N. Examining Health Care Costs Among MANNA Clients and a Comparison Group. J Prim Care Community Health. (2013) 4:311-317

[viii] Ibid.

[ix] Rabeneck L, Palmer A, Knowles JB, Seidehamel RJ, Harris CL, Merkel KL, Risser JMH, Akrabawi SS. A randomized controlled trial evaluating nutrition counseling with or without oral supplementation in malnourished HIV-infected patients. J Am Diet Assoc. (1998) 98: 434-438;Schwenk A, Steuck H, Kremer G. Oral supplements as adjunctive treatment to nutritional counseling in malnourished HIV-infected patients: randomized controlled trial. Clinical Nutrition (1999) 18(6): 371-374.

[x] M. S. Cohen *et al.*, Prevention of HIV-1 Infection with Early Antiretroviral Therapy. N. Engl. J. Med.(2011) 365, 493-505 . HPTN 052

[xi] Palar K, Laraia B, Tsai A, Weiser SD Food insecurity is associated with sexually transmitted infections and HIV serostatus among low income adults in the National Health and Nutrition Examination Survey (NHANES) (1999-2010). Presented at the American Public Health Association 141st Annual Meeting, Boston, MA, November 5, 2013.

[xii] Aidala A, Yomogida M, Vardy Y & the Food & Nutrition Study Team. Food and Nutrition Services, HIV Medical Care, and Health Outcomes. New York State Department of Health: Resources for Ending the Epidemic, 2014. Available at

xiii Weiser SD, Frongillo EA, Ragland K, Hogg RS, Riley ED, Bangsberg DR. Food insecurity is associated with incomplete HIV RNA suppression among homeless and marginally housed HIV-infected individuals in San Francisco. J Gen Intern Med. (2009) 24(1):14-20.

My name is Patrick O'Shaughnessy and I am the President of the Association of University Programs in Occupational Health and Safety (AUPOHS). On behalf of AUPOHS, an organization representing the 18 multidisciplinary, university-based Education and Research Centers (ERCs) and the ten Agricultural Centers for Disease and Injury Research, Education, and Prevention (Agricultural Centers) funded by the National Institute for Occupational Safety and Health (NIOSH), we respectfully request that the Fiscal Year 2017 Labor, Health and Human Services Appropriations bill include no less than $339.121 million for NIOSH, including $28.5 million for the Education and Research Centers and $25 million for the Agriculture, Forestry and Fishing (AFF) Program from which the Agricultural Centers receive their funding.

Occupational injury and illness represent a striking burden on America's health and well-being. Despite significant improvements in workplace safety and health over the last several decades, each day more than 8,000 workers are seriously injured on the job, 12 die from an injury suffered at work, and 145 die from work-related diseases. This huge health burden costs industry and citizens an estimated $4.8 billion per week. This is an especially tragic situation because work-related fatalities, injuries and illnesses most often affect the most productive individuals in our society and are preventable with effective, professionally directed, health and safety programs.

In addition to its extensive research mission, NIOSH is the federal agency responsible for supporting education and training to prevent work-related injuries and illnesses in the US. The ERCs are regional and national resources for parties involved with occupational health and safety – industry, labor, government, academia, and the public. Collectively, the ERCs provide training and research resources to every Federal Region in the US. ERCs contribute to national efforts to reduce losses associated with work-related illnesses and injuries by offering:

1) Prevention Research: Developing the basic knowledge and associated technologies to prevent work-related illnesses and injuries; 2) Professional Training: ERCs support graduate degree programs in Occupational Medicine, Occupational Health Nursing, Safety Engineering, Industrial Hygiene, and other related fields to provide qualified professionals in essential disciplines; 3) Research Training: Preparing doctoral-trained scientists who will respond to future research challenges and who will prepare the next generation of occupational health and safety professionals; 4) Continuing Education: Short courses designed to enhance professional skills and maintain professional certification for those who are currently practicing in occupational health and safety disciplines; and 5) Regional Outreach: Responding to specific requests from employers, health care professionals, and workers on issues related to occupational health and safety.

The rapidly changing workplace continues to present new health risks to American workers that need to be addressed through occupational safety and health research. For example, work related injury and fatality rates increase as workers get older, with rates for workers 65 years and older nearly three times greater than younger workers. For example, between 2002 and 2022, the number of workers 55 years and older will increase over 100% to over 41 million (BLS 2016). In addition to changing demographics, the rapid development of new technologies poses many unanswered questions with regard to workplace health and safety that require urgent attention. Newly emerging risks, such as Ebola and other infectious disease outbreaks, require swift responses to the need for worker protection.

The heightened awareness of terrorist threats, and the increased responsibilities of first responders and other homeland security professionals, illustrates the need for strengthened workplace health and safety in the ongoing war on terror. The NIOSH ERCs play a crucial role

in preparing occupational safety and health professionals to identify and mitigate vulnerabilities to terrorist attacks and to increase readiness to respond to biological, chemical, or radiological attacks. In addition, occupational health and safety professionals have worked for several years with emergency response teams to minimize disaster losses, including taking a lead role in protecting the safety of 9/11 emergency responders in New York City and Virginia, with ERC-trained professionals applying their technical expertise to meet immediate protective needs and to implement evidence-based programs to safeguard the health of clean-up workers.

In response to risks posed by potential Ebola exposure, ERCs have delivered educational programs and provided expertise in developing protocols and policies to prevent worker exposure. Additionally, NIOSH is the federal agency that is charged with certifying and approving the respirators that are required to protect U.S. workers.

We need manpower to address these challenges and it is the NIOSH ERCs that train the professionals who fill key positions in health and safety programs, regionally and around the nation. And because ERCs provide multi-disciplinary training, ERC graduates protect workers in virtually every walk of life.

NIOSH also focuses research and outreach efforts on the nation's most dangerous workplaces. People who work in agriculture, forestry and fishing experience occupational fatality rates that are 6 times to more than 32 times higher than the average for American workers. The Agricultural Centers program was established by Congress in 1990 (P.L. 101-517) in response to evidence that agricultural workers were suffering substantially higher rates of occupational injury and illness than other U.S. workers.

Today the NIOSH Agriculture, Forestry, and Fishing (AFF) Initiative includes nine regional Agricultural Centers and one national center to address children's farm safety and health. The

AFF program is the only substantive federal effort to meet the obligation to ensure safe working conditions in this most vital production sector. While agriculture, forestry, and fishing constitute one of the largest industry sectors in the U.S. (DOL 2011), most AFF operations are themselves small: nearly 78% employ fewer than 10 workers, and most rely on family members, immigrants, part-time, contract and/or seasonal labor. Many of these agricultural workers are excluded from labor protections, including OSHA oversight, on the vast majority of American farms.

The AFF sector averages 540 fatalities per year resulting in the highest fatality rate of any sector in the nation. More than 1 in 100 AFF workers incur nonfatal injuries resulting in lost work days each year. These reported figures do not even include men, women, and youths on the most dangerous farms – those with fewer than 11 full-time employees. In addition to the harm to individual men, women, and families, these deaths and injuries inflict serious economic losses including medical costs and lost capital, productivity, and earnings. The life-saving, cost-effective work of the NIOSH 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 NIOSH AFF program. In addition, staff members of USDA's National Institute of Food and Agriculture interact with NIOSH occupational safety and health research experts in order to learn about the cutting-edge research and new directions in this area.

NIOSH Agricultural Center activities include:

- AFF research has shown that the use of rollover protective structures (ROPS or rollbars) and seatbelts on tractors can prevent 99% of overturn-related deaths. A New York program has increased the installation of ROPS by 10-fold and recorded over 140 close calls with no

injuries among farmers who had installed ROPS. 99% of program participants said they would recommend the program to other farmers. Similar programs are now offered to prevent serious injuries due to entanglement in other farm machinery.

- Working in partnership with producers and farm owners, the Agricultural Centers have teamed to develop evidence-based solutions for reducing exposure to pesticides and other farm chemicals among farmers, farm workers and their children.
- Commercial Fishing has an annual fatality rate nearly 60 times higher than the rate for all U.S. workers. Research has shown that knowledge of maritime navigation rules and emergency preparedness means survival. An Agricultural Center team produced an interactive navigation training CD in three languages, demonstrated the effectiveness of refresher survival drill instruction, and assisted the US Coast Guard's revision of regulations requiring commercial fishing vessel captains complete navigation training.
- The NIOSH Agricultural Centers have partnered with producers, employers, the federal migrant health program, physicians, nurses, and Internet Technology specialists to educate farmers, employers, and health care providers about the best way to treat *and* prevent agricultural injury and illness.
- The logging industry has a fatality rate more than 25 times higher than that of all US workers. NIOSH Agricultural Centers have ongoing studies and outreach efforts to ensure the safety of our nation's 86,000 workers in forestry & logging.

Thank you for the opportunity to present testimony on behalf of the many individuals committed to working to improve the safety and wellbeing of others in our communities.

Contact: Maggie Elehwany
Vice President
Government Affairs and Policy
National Rural Health Association

Elehwany@nrharural.org
(202) 639-0550
1025 Vermont St. NW, Suite 1100
Washington, DC 20005

Testimony of the National Rural Health Association (NRHA)
Concerning HRSA's Programs Impacting Rural Health
Submitted for the Record to the House Committee on Appropriations Subcommittee on Labor, Health and Human Services, Education and Related Agencies – FY 2017

The National Rural Health Association (NRHA) is pleased to provide the Labor, Health and Human Services, Education and Related Agencies Appropriations Subcommittee with a statement for the record on fiscal year 2017 funding levels for programs with a significant impact on the health of rural Americans.

NRHA is a national nonprofit membership organization with a diverse collection of 21,000 individuals and organizations who share a common interest in rural health. The Association's mission is to improve the health of rural Americans and to provide leadership on rural health issues through advocacy, communications, education and research.

NRHA is advocating support for a group of rural health program that assist rural communities in maintaining and building a strong health care delivery system into the future. Most importantly, these programs help increase the capacity of the rural health care delivery system and true safety net providers. Rural Americans, on average, are poorer, sicker and older than their urban counterparts. Programs in the rural health safety net increase access to health care, help communities create new health programs for those in need and train the future health professionals that will care for the 62 million rural Americans. With modest investments, these programs evaluate, study and implement quality improvement programs and health information technology systems.

Funding for the rural health safety net is more important than ever as rural Americans are facing a hospital closure crisis. Seventy-one rural hospitals have closed, 10,000 rural jobs lost and 1.2 million rural patients have lost access to their nearest hospital since 2010. Even more

concerning is that 673 rural hospitals are at risk of closure, meaning sustained Medicare cuts threaten the financial viability of 1 in 3 rural hospitals. The loss of these hospitals would mean 11. 7 million patients would lose access to care in their community.

Important rural health programs supported by NRHA are outlined below.

The **National Health Service Corps (NHSC)** plays an important role in maintaining the health care safety net by placing primary health care providers in the most undeserved rural communities. NHSC is a network of 8,000 primary health care professionals, and 10,000 sites (September 2010). However, the demand for primary care providers far exceeds the supply, and the needs of rural communities continue to row. Rural communities must have the resources necessary to hire primary care, dental and behavioral health providers. Request: $278.3 million

Rural Health Outreach and Network Grants provide capital investment for planning and launching innovative projects in rural communities that will become self-sufficient. These grants are unique federal grants in that they allow a great deal of flexibility for the community to build a program around their community's specific needs. Grant funds are awarded for communities to develop needed formal, integrated networks of providers that deliver primary and acute care services. The grants have led to successful projects including information technology networks, oral screenings, and preventative care. Due to the community nature of the grants and the focus on sustainability after the grant term has run out – 85 percent of the grantees continue to deliver services a full five years after federal funding ends. Request: $69 million.

Rural Health Research and Policy Grants form the federal infrastructure for rural health policy. These grants provide policy makers with policy-relevant research on problems facing rural communities in providing access to quality affordable care and to improving population health in rural America. By funding rural health research centers across the country

These grants fund, these grants produce a mix of health services research, epidemiology, public health, geography, medicine, and mental health. These funds allow rural America to have a coordinated voice in the Department of Health and Human Services (HHS), in addition to providing expertise to agencies such as the Centers for Medicare and Medicaid Services. As a part of this request, we urge the Subcommittee to include in report language instructions to the Office of Rural Health Policy to direct additional funding to the state rural health associations. Request: $10.3 million.

State Offices of Rural Health provide state specific infrastructure for rural health policy. These state offices are the counterpart to the federal rural health research and policy framework. State offices form an essential link between small rural communities and the state and federal resources to develop long term solutions to rural health problems. These funds provide necessary capacity to states for the administration of critical rural health programs, assist in strengthening rural health care delivery systems, and maintaining rural health as a focal point within each state. The state offices play a key role in assisting rural health clinics, community health centers, and small, rural hospitals assess community health care needs. This program creates a state focus for rural health interests, brings technical assistance to rural areas, and helps frontier communities tap state and national resources available for health care and economic development. State offices form an essential connection to other state agencies and local communities; allowing federal resources to best address the unique needs of rural communities. Request: $15 million.

Rural Hospital Flexibility Grants fund quality improvement and emergency medical service projects at Critical Access Hospitals (CAHs). These grants allow rural communities to improve access to care, develop increased efficiencies, and improved quality of care by

leveraging the services of CAHs, Emergency Medical Services (EMS), clinics, and health practitioners. These grants serve an important function in increasing information technology activities in rural America. Also funded in this line is the Small Hospital Improvement Program (SHIP), which provides grants to more than 1,500 small rural hospitals (50 beds or less) across the country to improve business operations, focus on quality improvement, and ensure compliance with health information privacy regulations. Request: $46 million.

Rural and Community Access to Emergency Devices Grants help communities afford the purchase of emergency devices, such as defibrillators, and the necessary training for community members and first responders in the proper use of these devices. The proper and timely use of a defibrillator following a sudden cardiac arrest doubles a victim's change of survival. Placement of devices within the community where cardiac arrest is likely to occur allows for greater success. Such immediate intervention are particularly important in rural America where follow on medical care may require longer wait times due to long distances to a hospital, mountainous terrain, or inclement weather. Request: $4.5 million.

The Office for the Advancement of Telehealth (OAT) supports the provision of clinical services at a distance, reduces rural provider isolation, fosters integrated delivery systems through network development, and tests a broad range of telehealth applications. Long-term, telehealth promises to improve the health of millions of Americans, save money by reducing unnecessary office visits and hospital stays, and provide continuing education to isolated rural providers. The OAT coordinates and promotes the use of telehealth technologies by fostering partnerships between federal and state agencies and private sector groups. Since telehealth is still an emerging field with new approaches and technologies; continued investment in the infrastructure and development is needed. Request: $18.5 million.

Title VII Health Professions Training Programs (with a significant rural focus):

• **Area Health Education and Centers (AHECs)** encourage and provide financial support to those training to become health care professionals in rural areas. Without this experience and support in medical school, far fewer professionals would be aware of the needs of rural communities and even fewer would make the commitment to practice in rural areas. AHECs support the recruitment and retention of physicians, students, faculty and other primary care providers in rural and medically underserved areas. It has been estimated that nearly half of AHECs would shut down without federal funding, placing future access to health care in rural communities at risk. Request: $40 million.

• **Rural Physician Pipeline Grants** help medical colleges develop rural specific curriculum and to recruit students from rural communities that are likely to return to their home regions to practice. This "grow-your-own" approach is one of the best and most cost-effective ways to ensure a robust rural workforce into the future. Request: $5.3 million.

• **Geriatric Programs** train health professionals in geriatrics, including funding for Geriatric Education Centers (GEC). There are currently 47 GECs nationwide that ensure access to appropriate and quality health care for seniors. Rural America has a disproportionate share of our nation's elderly and is more likely to have physician shortages than urban locations. Without this program, rural health care provider shortages would grow. Request: $42 million.

The National Rural Health Association appreciates the opportunity to provide our recommendations to the Subcommittee. These programs are critical to the rural health delivery system and help maintain access to high quality care in rural communities. We greatly appreciate the support of the Subcommittee and look forward to working with Members of the Subcommittee to continue making these important investments in rural health.

Friends of the Health Resources and Services Administration
c/o American Public Health Association • 800 I Street NW • Washington, DC, 20001 • 202-777-2742

Nicole Burda, Deputy Director of Government Relations, American Public Health Association
Testimony submitted for the record on April 13, 2016
House Committee on Appropriations Subcommittee on Labor, Health and Human Services, and Education and Related Agencies

Friends of HRSA is a nonpartisan coalition of 170 national organizations representing millions of public health and health care professionals, academicians and consumers invested in the Health Resources and Services Administration's mission to improve health and achieve health equity. For fiscal year 2017, we recommend restoring HRSA's discretionary budget authority to the FY 2010 level of $7.48 billion. HRSA is the primary federal agency responsible for improving health, and does so through access to quality health services, a skilled workforce and innovative programs. Over the past three years, HRSA's discretionary budget authority has slowly been restored, but still remains nearly 18 percent below the FY 2010 level – far too low to fully address the nation's current health needs. Restoring funding to HRSA will allow the agency to more effectively fill preventive and primary care gaps.

Our nation's ability to deliver health services that meet the pressing health challenges of the 21st century is essential for a healthy and thriving population. To meet our nation's persistent and changing health needs, and to keep pace with our growing, aging and diversifying population, and evolving health care system, we must make deliberate investments in robust systems of care and a high-performing workforce ready to respond to the current demands and able to take on unexpected health needs as they arise. The agency is continuously exploring and supporting efforts that drive quality care, better leverage existing investments and achieve improved health outcomes at a lower cost. HRSA's programs have been successful in improving the health of people at highest risk for poor health outcomes.

HRSA operates programs in every state and U.S. territory. The agency is a national leader in improving the health of Americans by addressing the supply, distribution and diversity of health professionals and supporting training in contemporary practices, and providing quality health services. HRSA programs work in coordination with each other to maximize resources and leverage efficiencies. For example, Area Health Education Centers, a health professions training program, was originally authorized at the same time as the National Health Service Corps to create a complete mechanism to provide primary care providers for health centers and other direct providers of health care services for underserved areas and populations. AHECs serve as an integral part of the mechanism that recruits providers into primary health careers, diversifies the workforce and develops a passion for service to the underserved in these future providers.

HRSA's programs also work synergistically across the federal government to enhance health outcomes. Through maternal and child health programs, HRSA has contributed to the decrease in infant mortality rate, a widely used indicator of the nation's health. While HRSA has contributed to driving down the national rate, which is now at a historic low of 5.8 deaths per 1,000 live births, it would not have been possible without the effort of other federal public health programs, including those that address perinatal care, cessation programs for tobacco and other substances, healthy eating and physical activity programs, among other efforts.

HRSA grantees also have the potential to play an active role in addressing emerging health challenges. For example, HRSA's programs are well positioned to provide outreach, education, prevention, screening and treatment services for populations at risk for or infected with the Zika virus and are already doing so in Puerto Rico and affected territories. However, as we approach warmer months and the opportunity to encounter mosquitos that can spread the Zika virus increases, additional funding will be required to increase capacity in health centers, support additional National Health Service Corps providers to deliver the care needed and

expand maternal and child health services. Strong, sustained funding would allow HRSA to build a consistent approach to quickly and effectively respond to emerging and unanticipated future needs, while continuing to address persistent health challenges.

Our recommendation is based on the need to continue improving the health of Americans and to provide HRSA with the resources needed to pave the way for new achievement by supporting critical HRSA programs, including:

- Primary care programs support more than 9,000 health center sites in every state and territory, improving access to preventive and primary care for more than 22.9 million patients in geographic areas with few health care providers. Health centers coordinate a full spectrum of health services including medical, dental, behavioral and social services. Close to half of all health centers serve rural populations. For 50 years, health centers have delivered comprehensive, cost-effective care for people who otherwise may not have obtained care and have demonstrated their ability to reduce the use of costlier providers of care.
- Health workforce programs support the education, training, scholarship and loan repayment of primary care physicians, nurses, oral health professionals, optometrists, physician assistants, nurse practitioners, clinical nurse specialists, public health personnel, mental and behavioral health professionals, pharmacists and other allied health providers. With a focus 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 distribution and diversity of the workforce so that health professionals are well-equipped to care for the nation's changing needs and demographics.
- Maternal and child health programs, including the Title V Maternal and Child Health Block Grant, Leadership Education in Neurodevelopmental and Related Disabilities, Healthy Start and others support initiatives designed to promote optimal health, reduce disparities, combat

infant mortality, prevent chronic conditions and improve access to quality health care for 34.3 million children. 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, and also help improve early identification and coordination of care for children with autism and other developmental disabilities.

- HIV/AIDS programs provide the largest source of federal discretionary funding assistance to states and communities most severely affected by HIV/AIDS. The Ryan White HIV/AIDS Program delivers comprehensive care, prescription drug assistance and support services to 512,000 people living with HIV/AIDS, which accounts for nearly half of the total population living with the disease in the U.S. Additionally, the programs provide education and training for health professionals treating people with HIV/AIDS and work toward addressing the disproportionate impact of HIV/AIDS on racial and ethnic minorities. People receiving care through the Ryan White HIV/AIDS Program achieve significantly higher viral suppression compared to the national average, and viral suppression is central to preventing new HIV infections.
- Family planning Title X services ensure access to a broad range of reproductive, sexual and related preventive health services for more than 4.1 million low-income women, men and adolescents. Services include patient education and counseling, cervical and breast cancer screening, sexually transmitted disease prevention education, testing and referral, as well as pregnancy diagnosis and counseling. This program helps improve maternal and child health outcomes and promotes healthy families. In 2014, Title X family planning helped prevent over 941,000 unintended pregnancies and an estimated 1,176 cases of sexually transmitted disease-related infertility.

- Rural health programs improve access to care for people living in rural areas. The Office of Rural Health Policy serves as the nation's primary advisor on rural policy issues, conducts and oversees research on rural health issues and administers grants to support health care delivery in rural communities. Rural health programs are designed to support community-based disease prevention and health promotion projects, help rural hospitals and clinics implement new technologies and strategies and build health system capacity in rural and frontier areas. In addition to improving the health of rural residents, an analysis completed in 2013 showed that for every dollar HRSA invested, about $1.63 in additional revenue was generated in the community – the cumulative impact added up to $19.4 million in new local economic activity over a three-year project period of an original investment of $11.9 million.
- 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.

We urge you to consider HRSA's central role in strengthening the nation's health and advise you to adopt our FY 2017 request of $7.48 billion for HRSA's discretionary budget authority. Thank you for the opportunity to submit our recommendation to the subcommittee.

RAILROAD RETIREMENT BOARD
OFFICE OF INSPECTOR GENERAL
FISCAL YEAR 2017 BUDGET REQUEST

SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES, EDUCATION AND RELATED AGENCIES OF THE COMMITTEE ON APPROPRIATIONS U.S. HOUSE OF REPRESENTATIVES

MARTIN J. DICKMAN, INSPECTOR GENERAL
Martin.Dickman@oig.rrb.gov
(312) 751-4690

STATEMENT FOR THE RECORD

April 15, 2016

Mr. Chairman and Members of the Subcommittee:

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

BUDGET REQUEST

The President's proposed budget for Fiscal Year (FY) 2017 would provide $10,499,000 to the Office of Inspector General (OIG) to ensure the continuation of the OIG's independent oversight of the Railroad Retirement Board (RRB). During FY 2017, the OIG will focus on areas affecting program performance; the efficiency and effectiveness of agency operations; and areas of potential fraud, waste and abuse.

OPERATIONAL COMPONENTS

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

OFFICE OF AUDIT

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

During FY 2017, OA will focus on areas affecting program performance; the efficiency and effectiveness of agency operations; and areas of potential fraud, waste, and abuse. OA will continue its emphasis on long-term systemic problems and solutions, and will address major issues that affect the RRB's service to rail beneficiaries and their families. OA has identified six broad areas of potential audit coverage: Financial Accountability; Railroad Retirement Act and Railroad Unemployment Insurance Act Benefit Program Operations; RRB Contracts and Contracting Activities; Railroad Medicare Program Operations; Security, Privacy, and Information Management; and Improper Payments Act of 2010 Oversight.

OA must also accomplish the following mandated activities with its own staff: Audit of the RRB's financial statements pursuant to the requirements of the Accountability of Tax Dollars Act of 2002; evaluation of information security pursuant to the Federal Information Security Management Act (FISMA); audit of the RRB's compliance with the Improper Payments Elimination and Recovery Act of 2010; review of IG Requirements for Government Charge Card Abuse and Prevention Act of 2012; assessments required under the Digital Accountability and Transparency Act of 2014; and semi-annual reporting in accordance with the Inspector General Act of 1978, as amended.

During FY 2017, OA will complete the audit of the RRB's FY 2016 financial statements and begin its audit of the agency's FY 2017 financial statements. OA contracts with a consulting actuary for technical assistance in auditing the RRB's "Statement of Social Insurance", which became basic financial information effective in FY 2006. In addition to performing the annual evaluation of information security, OA also conducts audits of individual computer application systems which are required to support the annual FISMA evaluation. Our work in this area is targeted toward the identification and elimination of security deficiencies and system vulnerabilities, including controls over sensitive personally identifiable information.

OA undertakes additional projects with the objective of allocating available audit resources to areas in which they will have the greatest value. In making that determination, OA considers staff availability, current trends in management, and Congressional and Presidential concerns. Mandated audits are increasing, and additional resources will make it possible for OA to provide additional oversight to programs that represent billions in taxpayer dollars.

OFFICE OF INVESTIGATIONS

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

OI Investigative Results for FY 2015

Civil Judgments	Indictments/Informations	Convictions	Recoveries/Receivables
27	49	43	$203,692,184 1/

OI anticipates an ongoing caseload of about 350 investigations in FY 2017. During FY 2015, OI opened 186 new cases and closed 212. At present, OI has cases open in 48 states, the District of Columbia, and Canada with estimated fraud losses of over $596 million. Disability and Medicare fraud cases represent the largest portion of OI's total caseload. These cases involve more complicated schemes and often result in the recovery of substantial amounts for the RRB's trust funds. They also require considerable resources such as travel by special agents to conduct surveillance, numerous witness interviews, and more sophisticated investigative techniques. Additionally, these fraud investigations are extremely document-intensive and require forensic financial analysis.

1/ This total amount of financial accomplishments reflect fraud amounts related to programs administered exclusively by the RRB and fraud amounts from other Federal Programs such as Medicare or Social Security, which were included in the disposition resulting from the investigation.

Of particular significance is an ongoing disability fraud investigation related to a large number of individuals in New York. To date, this investigation has resulted in 33 individuals pleading guilty or being convicted in Federal court. All individuals prosecuted in connection with this case have been sentenced. This investigation is continuing, and there is the potential for more charges in this case. OI agents will likely have to spend a considerable amount of time traveling to New York for continuing investigations. Based on this investigation, the OI has initiated several other large scale disability investigations that could result in significant charges being filed.

During FY 2017, OI will continue to coordinate its efforts with agency program managers to address vulnerabilities in benefit programs that allow fraudulent activity to occur and will recommend changes to ensure program integrity. OI plans to continue proactive projects to identify fraud matters that are not detected through the agency's program policing mechanisms.

CONCLUSION

In FY 2017, the OIG will continue to focus its resources on the review and improvement of RRB operations and will conduct activities to ensure the integrity of the agency's trust funds. This office will continue to work with agency officials to ensure the agency is providing quality service to railroad workers and their families. The OIG will also aggressively pursue all individuals who engage in activities to fraudulently receive RRB funds. The OIG will continue to keep the Subcommittee and other members of Congress informed of any agency operational problems or deficiencies.

Association of American Cancer Institutes

Statement by the Association of American Cancer Institutes on
Fiscal Year (FY) 2017 Appropriations for the Department of Health and Human Services
Subcommittee on Labor, Health and Human Services, Education, and Related Agencies
Committee on Appropriations, U.S. House of Representatives

The Association of American Cancer Institutes (AACI), representing 95 premier academic and free-standing cancer centers, appreciates the opportunity to submit this statement for consideration by the subcommittee. Barbara Duffy Stewart, Executive Director of AACI submits this request for the Department of Health and Human Services budget for the National Institutes of Health (NIH) in the amount of at least $34.5 billion for Fiscal Year (FY) 2017. In light of President Obama and Vice President Biden's National Cancer Moonshot initiative, we request that funding for the National Cancer Institute (NCI) be prioritized and that NCI receive at least $5.9 billion, in order to begin the initiative.

AACI appreciated Congress' FY 2016 bipartisan spending bill, which provided the NIH with the largest boost in annual appropriations since FY 2003. AACI cancer centers believe the partnership between the federal government and academic cancer centers is cooperative, and cancer centers continue to make strides in biomedical research thanks to the support of the federal government. Without such support, research projects with the potential to discover breakthrough therapies would not be possible.

The President's FY 2017 Budget Blueprint

The President's FY 2017 budget request for the NIH is $33.136 billion, $825 million above the enacted FY 2016 level. This includes $5.893 billion for the NCI. In his budget blueprint, the President outlined the National Cancer Moonshot initiative, which includes an investment of $680 million, as well as $100 million for the Precision Medicine Initiative.

AACI cancer centers are at the forefront of the national effort to eradicate cancer. The cancer centers that AACI represents house more than 20,000 scientific, clinical and public health investigators who work collaboratively to translate promising research findings into new approaches to prevent and treat cancer. Making progress against cancer is complex and time-intensive. However, the pace of discovery and translation of novel basic research to new therapies could be accelerated if researchers could count on an appropriate and predictable investment in federal cancer funding.

While the President's proposed budget would allow for 36,440 competing Research Project Grants (RPG's) in 2017, an increase from the 35,840 RPG's in 2016, academic cancer centers nationwide continue to grapple with budget constraints and the issue of investigator retention. Uncertainty surrounding RPG's and cancer center resources often drives promising scientists to explore opportunities abroad or outside of the biomedical research community. For most academic cancer centers, the majority of NCI grant funds are used to sustain shared resources that are essential to basic, translational, clinical and population cancer research, or to provide matching dollars which allow departments to recruit new cancer researchers to a university and support them until they receive their first grants. It is imperative that we enable America's scientists to master their craft.

Therefore, AACI requests that Congress surpass the President's budget request and provide the NIH with at least $34.5 billion for FY 2017. AACI is encouraged by the National Cancer Moonshot initiative and requests that the NCI receive at least $5.9 billion in FY 2017.

National Cancer Moonshot Initiative

AACI cancer centers are invigorated by the National Cancer Moonshot initiative and their potential to contribute to the elimination of cancer. A goal of the "moonshot" initiative is

collaboration among academic institutions and revolutionizing the sharing of medical and research data. AACI cancer centers are a primary source for the generation, collection and use of molecular, clinical and outcomes data. Steady, predictable funding for the NIH and NCI is vital as cancer centers work to share data and improve information systems and communication across the cancer continuum.

The "moonshot" initiative also aims to accomplish a decade's worth of advances in five years, making new therapies available to patients, while also improving our ability to prevent and detect cancer at an early stage. Prevention and early detection are highly important to AACI cancer centers, as they offer patients the latest advances in cancer prevention, detection, diagnosis, and treatment.

AACI member centers value the renewed investment in biomedical research supported by the NIH and the NCI, but robust funding for these important agencies will be necessary in order to accept the call for a "moonshot" and accelerate scientific progress. Peaks and valleys in the NIH and NCI budget merely slow advances in biomedical research and also undermine cancer centers' ability to: conduct and support multidisciplinary cancer research; train cancer physicians and scientists; provide state-of-the-art care; and, disseminate information about cancer detection, diagnosis, treatment, prevention, control, palliative care, and survivorship across our communities.

With excitement mounting about the scientific opportunities ahead and our potential to leverage the resulting advances to benefit cancer patients nationwide, it is imperative that Congress fully fund the agencies responsible for advancing cancer research. The broad portfolio of science supported by the NIH and NCI is essential for improving our basic understanding of cancer and has contributed to the health and well-being of Americans.

Cancer: Then and Now

Progress in cancer research has reached unprecedented levels since the enactment of the National Cancer Act in 1971, yet cancer remains one of the leading causes of death and disability in the United States. This year, nearly 1.7 million Americans will receive a cancer diagnosis and more than 595,000 Americans will lose their lives to cancer. [1] As the population ages, cancer incidence is expected to grow significantly, reaching 2.3 million diagnoses per year by 2030.[2]

Despite these alarming statistics, progress continues to be made in cancer research, discovery, and the delivery of care. The five-year survival rate for all types of cancer was greater than 65 percent in 2011, improving between 1981 and 2011, and more than 14.5 million cancer survivors were living in the U.S. in 2015.[3] The improvement in survival reflects the advances being made by diagnosing cancers at an earlier stage and providing better treatments to cancer patients.

The Agency for Healthcare Research and Quality estimates that the direct medical costs (total of all health care expenditures) for cancer in the U.S. were $74.8 billion in 2013.[4] Even as the cost of cancer continues to rise, investment in cancer research could one day significantly reduce or even eliminate the health and economic burden that cancer imposes on all Americans. Ensuring stable, predictable funds are provided to the NIH and NCI will aid our nation's cancer center researchers in discoveries which ultimately improve cancer treatment outcomes.

Conclusion

Our country has contributed to a steady decrease in the mortality rate for cancer, but America can do better. Now is the time for Congress to invest in biomedical research in general

[1] American Cancer Society. Facts and Figures, 2016. http://www.cancer.org/acs/groups/content/@research/documents/document/acspc-047079.pdf

[2] Smith BD, Smith GL, Hurria A, Hortobagyi GN, Buchholz TA. Future of cancer incidence in the United States: burdens upon an aging, changing nation. J Clin Oncol. 2009 Jun 10;27(17):2758-65.

[3] American Cancer Society. Facts and Figures.

[4] American Cancer Society. Facts and Figures.

and cancer research in particular. AACI joins our colleagues in the biomedical research community in recommending that the subcommittee recognize the NIH as a critical national priority by providing at least $34.5 billion in funding in the FY 2017 Labor-HHS-Education Appropriations bill. Additionally, we ask that the subcommittee funds the NCI with at least $5.9 billion in funding for FY 2017.

A robust federal investment in our nation's NCI-designated cancer centers and emerging academic cancer centers will allow the cancer community to heed the call for a "moonshot to cure cancer." This is an important moment in our nation's history and we ask the subcommittee to invest in academic cancer centers as they work to accomplish the goal to end cancer for the good of our country.

Name: Heather Barcal

Title: Community Outreach Administrative Assistant

Institutional Affiliation (if any): Lake County Center for Independent Living

This testimony is prepared for the House Committee on Appropriations Subcommittee on Labor, Health and Human Services, Education, and Related Agencies.

Dear Committee Members:

I write to support the National Council on Independent Living's request for Congress to reaffirm your commitment to the more than 57 million Americans with disabilities by increasing funding in the HHS appropriations for Centers for Independent Living (CILs). I ask that you increase funding by $200 million, for a total of $301 million for the Independent Living line item in FY 2017.

This money will be used to assist people with disabilities to live independently in their own homes, rather than in institutions where they do not belong. In the long run, it saves the government millions of dollars each year. While an additional $200 million seems like a lot of money, it will balance out with the savings in Medicaid and Medicare dollars no longer wasted to pay for institutional living. Community-based services, such as those provided by CILs, enable people with disabilities to become less reliant on long-term government supports, Simpley put, you are more likely to get a job and support yourself if you are living in your home as opposed to a nursing home.

Each of the 365 federally funded centers provides five core services: information and referral, individual and systems advocacy, peer support, independent living skills training, and transition

services. Transition was added as a core service with the passage of the Workforce Innovation and Opportunity Act (WIOA). The passage of WIOA was a huge step in supporting independent living services, but its mandates were left unfunded. Specifically, the mandates provide that CILS transition individuals with significant disabilities from nursing homes and other institutions to home and community-based residences, assist individuals with significant disabilities at risk of entering institutions to remain in the community, and assist youth with significant disabilities to transition into postsecondary life. This core service is vital to achieving full participation for people with disabilities.

The appropriation we request will also help to restore the devastating cuts to the Independent Living program, make up for inflation costs, and address the increased demand for independent living services. It is simply not possible to meet the increasing demand for services and effectively provide transition services without additional funding. Increased funding should be reinvested from the billions currently spent to keep people with disabilities in costly nursing homes and institutions.

Centers for Independent Living play a crucial role in the lives of people with disabilities, and work tirelessly to ensure that people with disabilities have a real choice in where and how they live, work, and participate in the community. Additionally, CILs are an excellent service and a bargain for America, keeping people engaged with their communities and saving taxpayer money. NCIL is dedicated to increasing the availability of the invaluable and extremely cost-effective services CILs provide, and they have submitted written testimony with a similar request. I strongly support NCIL's testimony and ask that you support this appropriation.

Anna Liwbenow

I am writing to support the National Council on Independent Living's request for Congress to reaffirm your commitment to the more than 57 million Americans disabilities by increasing funding in the HHS appropriations for Centers for Independent Living (CILs). I am asking that you increase funding by $200 million, for a total of $301 million for the Independent Living line item in FY 2017.

CILs are cross-disability, non-residential, community-based, nonprofit organizations that are designed and operated by individuals with disabilities. CILs are unique in that they are directly governed and staffed by people with all types of disabilities, including people with mental, physical, sensory, cognitive, and developmental disabilities. Each of the 365 federally funded centers provides five core services: information and referral, individual and systems advocacy, peer support, independent living skills training, and transition services, which were added with the passage of the Workforce Innovation and Opportunity Act (WIOA). From 2012-2014, CILs provided the core services to nearly 5 million people with disabilities, and provided additional services such as housing assistance, transportation, personal care attendants, and employment services to hundreds of thousands of individuals. During this same period, prior to transition being added as a core service, CILs transitioned 13,030 people with disabilities from nursing homes and other institutions into the community.

Transition services were added as a fifth core service with the 2014 reauthorization of the Rehabilitation Act within the Workforce Innovation and Opportunity Act. Transition services

include the transition of individuals with significant disabilities from nursing homes and other institutions to home and community-based residences with appropriate supports and services, assistance to individuals with significant disabilities at risk of entering institutions to remain in the community, and the transition of youth with significant disabilities to postsecondary life. This core service is vital to achieving full participation for people with disabilities.

Every day, CILs are fighting to ensure that people with disabilities gain and maintain control over our own lives. We know that this cannot occur when people reside in institutional settings. Opponents of deinstitutionalization say that allowing people with disabilities to live in the community will result in harm. We know that the 13,030 people with disabilities who CILs successfully transitioned out of nursing homes and institutions from 2012-2014 prove otherwise. Additionally, when services are delivered in an individual's home, the result is a tremendous cost savings to Medicaid, Medicare, and states. Community-based services enable people with disabilities to become less reliant on long-term government supports, and they are significantly less expensive than nursing home placements. We are grateful that Congress demonstrated their understanding and support for community-based services when WIOA was passed and transition was added as a fifth core service.

Since transition services were added as a core service, the need for funding is critical. Moreover, CILs need additional funding to restore the devastating cuts to the Independent Living program, make up for inflation costs, and address the increased demand for independent living services. In 2016, the Independent Living Program is receiving $2.5 million less in funding than it was in 2010. It is simply not possible to meet the increasing demand for services and effectively provide

transition services without additional funding. Increased funding should be reinvested from the billions currently spent to keep people with disabilities in costly Medicaid nursing homes and institutions and out of mainstream society.

Centers for Independent Living play a crucial role in the lives of people with disabilities, and work tirelessly to ensure that people with disabilities have a real choice in where and how they live, work, and participate in the community. Additionally, CILs are an excellent service and a bargain for America, keeping people engaged with their communities and saving taxpayer money. NCIL is dedicated to increasing the availability of the invaluable and extremely cost-effective services CILs provide, and they have submitted written testimony with a similar request. I strongly support NCIL's testimony.]

Testimony of Stephen DeWitt
Deputy Executive Director
Association for Career and Technical Education

Subcommittee on Labor, Health and Human Services, Education, and Related Agencies
Committee on Appropriations
U.S. House of Representatives

April 15, 2016

Chairman Cole, Ranking Member DeLauro and members of the subcommittee, on behalf of the Association for Career and Technical Education (ACTE), the nation's largest not-for-profit association committed to the advancement of education that prepares youth and adults for successful careers, I would like to urge you to help support career and technical education (CTE) through a strong federal investment in the Carl D. Perkins Career and Technical Education Act (Perkins) for Fiscal Year (FY) 2017. To ensure that students are equipped with the academic, technical and employability skills they need for success in the jobs that are available today, and the careers of tomorrow, I respectfully request that the subcommittee increase the Perkins Basic State Grant program (Title I), administered by U.S. Department of Education, Office of Career, Technical, and Adult Education, to $1.3 billion in the FY 2017 Labor, Health and Human Services, and Education appropriations bill.

Perkins is the principal source of dedicated federal funding for CTE programs in secondary and postsecondary institutions across the county. This federal investment is crucial to ensuring that students are prepared for careers in expanding fields like engineering, information technology, advanced manufacturing and health care. In a rapidly changing job market, CTE provides students with transferable skills that ensure they are college-and career-ready, while offering retraining opportunities to many working adults.

Despite the importance of Perkins funding in advancing high-quality CTE programs for more than 11 million students nationwide, congressional appropriations have not kept pace with the growing need. Funding for the Perkins Basic State Grant program is still $5.4 million below its pre-sequestration level. From FY 2007 through FY 2016, total Perkins grant funding to states declined by 13 percent—nearly $170 million less in funding to support CTE, and an even greater loss if you take into account the effects of inflation.

The erosion of Perkins funds comes at a time when CTE programs are experiencing new attention and growth. States are using Perkins funding to strengthen student performance

results in areas such as attainment of academic and technical skills, and transitioning to further education or employment. In the most recent data available, the average high school graduation rate for students concentrating in CTE programs is 93 percent. Students involved in CTE programs are engaged in their education, perform well academically, gain critical employability skills and earn industry-recognized credentials. Perkins provides a strong return on our federal investment by fostering an educated and highly skilled workforce that delivers direct benefits to American employers, and further strengthens the economy through productivity and innovation.

The Obama Administration's FY 2017 budget request includes an increase of $75 million for the proposed American Technical Training Fund, which would provide competitive grants to support the development job training programs in high-demand fields. The additional request of a $2 million increase for CTE National Programs would provide technical assistance and evaluation support for projects under the American Technical Training Fund proposal. While these resources would help meet the needs of a few programs, the Administration's budget, once again, fails to provide any additional funding for the formula Perkins Basic State Grant program. It is the position of ACTE that limited resources for education and job training are better directed to proven, formula-driven programs that serve students in communities across the country, and we remain committed to expanding equitable access to high-quality CTE.

Increasing the Perkins Basic State Grant to $1.3 billion, a 15 percent increase over the current level, would restore funding for states to the FY 2007 level and could support an additional 1.7 million students by expanding access to CTE programs of study that create a seamless educational pathway by strengthening the integration of academics and CTE content in the classroom, providing career guidance and academic counseling services, ensuring that CTE classrooms have the latest technology and equipment, and providing professional development and technical assistance for CTE educators. Thank you for your continued leadership and for your thoughtful consideration of our request. We look forward to working in a bipartisan fashion with the subcommittee throughout the FY 2017 appropriations process.

Julie M. Vose, MD, MBA, FASCO
President
American Society of Clinical Oncology

Statement for the Record prepared for:

Subcommittee on Labor, Health and Human Services, Education, and Related Agencies, United States House of Representatives Committee on Appropriations

Regarding funding for the National Cancer Institute and the National Institutes of Health for FY 2017

April 14, 2016

The American Society of Clinical Oncology (ASCO), the world's leading professional organization representing nearly 40,000 physicians and other professionals who treat people with cancer, appreciates this opportunity to provide the following recommendations for Fiscal Year 2017 (FY 2017) funding:

- National Institutes of Health (NIH): $34.5 billion
- National Cancer Institute (NCI): $5.9 billion

ASCO's members set the standard for cancer care world-wide and lead the way in carrying out translational and clinical research aimed at improving the screening, prevention, diagnosis and treatment of cancer. ASCO advocates for policies that provide access to high-quality care for all patients with cancer. ASCO's efforts are also directed toward supporting oncology clinical and translational research that is critical to improving the lives of our citizens and that can inform cancer services for people worldwide.

Building on Last Year's Progress: NIH and NCI Need a Plan for Sustained Funding Growth

Federal funding for cancer research has led to significant advances in cancer prevention, detection, diagnosis, treatment, and quality of life over the last half century. When it comes to high-risk, pioneering research, federal funding is indispensable. Federally funded research also helps answer critical patient care questions that private industry research is unlikely to address. More than 14.5 million cancer survivors are alive in the United States today, largely because of the nation's commitment to cancer research. Further NIH investment improves not only the health of Americans but the wealth of our nation as a whole. NIH funding creates jobs and return on investment for local economies in all fifty states. On a global level, this investment protects America's leadership and admired biomedical research infrastructure.

ASCO thanks this subcommittee for its work to secure the largest increase for the NIH in over a decade in the FY16 appropriations process. We appreciate the difficult decisions you face. If we are to conquer cancer, we need to invest more as a nation so that we can prepare for what lies ahead. Cancer care is set to change more dramatically in the next 20 years than it did in the last 50, thanks in part to advances in health information technology and a deeper understanding of cancer's molecular drivers. As biomedical discovery expands, we need to be able to answer difficult questions and pursue new research directions.

When it comes to high-risk, pioneering research, federal funding is indispensable. The NIH is uniquely positioned to conduct research where pharmaceutical companies may not have an incentive; including combination therapies and head-to-head comparative trials. Federally funded research also helps answer critical patient care questions that private industry research is unlikely to address. Such questions assume even greater importance as our healthcare system strives to improve efficiency and deliver high value care in an era when patients often have multiple treatment options available.

ASCO's 2016 *Clinical Cancer Advances* report (http://www.cancerprogress.net/sites/cancerprogress.net/files/asco-cca16-web-updated.pdf) features examples of notable research successes achieved thanks to funding from the NIH, including:

- A large, nationwide analysis that found remarkable improvements in long-term childhood cancer survival rates over three decades.
- A large clinical trial that revealed an additional hormone treatment option to reduce the risk of new or recurrent breast cancer after ductal carcinoma in situ (DCIS).
- An early clinical trial that showed that a combination of two novel *targeted drugs* (aimed at abnormalities in the cancer cell) may slow the growth of a difficult-to-treat form of ovarian cancer.
- A clinical trial that demonstrated that avoiding whole brain irradiation for limited brain metastases helps preserve patient quality of life.
- New evidence confirming that early *palliative care* not only extends patients' lives but can also benefit caregivers.

Progress is hampered not by the lack of ideas but by insufficient resources. As oncologists, we owe it to our patients to pursue every option possible in cancer treatment and supportive care. Our nation's commitment to support a strong federally funded US research enterprise ensures that we are well-positioned to deliver the care our patients deserve. Critical areas where federal resources must meet opportunity are; big data, the Cancer Moonshot Initiative including precision medicine, and clinical trials and translational research.

Supporting Pillars of Care: Clinical Trials and Translational Research

Federal funding and targeted programs bring clinical trials to community practices that involve a great number of participants and that have the capacity to include diverse groups of participants. NIH-funded translational research and clinical trials have significantly improved the standard of care in many diseases. At the same time, they also have demonstrated more cost-effective treatment options for many common cancers and provided knowledge to target therapies to patients most likely to benefit and help others avoid ineffective therapies. This is where science becomes practice changing for patients in America.

In advance of ASCO's 2016 Annual Meeting, 5817 research abstracts were submitted for presentation. 1,995 of those abstracts reported that the study was a clinical trial. Among those studies, only 146 reported having received federal funding from the NIH. This is a 26.6% decline from the number of federally funded clinical trials studies submissions reported in 2015. This statistic represents an overall alarming trend of fewer federally funded clinical trials and declining enrollment.

To maintain access to research for community 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 the overall federal funding situation is causing NCI to be unable to support these programs at needed levels because of an ever-shrinking pot. An increase in NCI funding would enable the Institute to maintain or increase the number of accruals to trials at the same time as it increases payments to cover the cost of conducting the research.

Capturing Opportunity: the Cancer Moonshot Initiative

As a community of providers and researchers, we are inspired by the President's call for a Cancer Moonshot and support the proposed increase in funding directed towards accelerating progress in preventing, diagnosing, and treating cancers. ASCO is appreciative to Congress for passing the 2016 budget deal. We hope last year's increase will be used as first step in a plan for sustained growth. The proposed increases for the NIH, especially for the NCI and Precision Medicine Institute (PMI) are essential to restore funding shortfalls that have severely hampered progress in the last decade and will build on the support provided by Congress in FY16.

Precision medicine research work will help accelerate the development and broader application of targeted therapies for cancer patients. As detailed in *ASCO's 2016 Clinical Cancer Advances* report, targeted therapy is designed to target molecules precisely in or on cancer cells or in the tissue surrounding a tumor. Genetic changes can cause cells to make too much of a certain protein or to produce abnormal proteins. Targeted therapy works by blocking or switching off such proteins that cause the cells to keep growing and dividing. Precision medicine builds on the ever-expanding understanding of tumor biology. Several recent advances illustrate how

specific molecular vulnerabilities in cancer can be exploited to develop powerful new treatments.

In 2015, researchers reported remarkable success with targeted therapy, with a range of new treatments that slow the growth of advanced cancers. The FDA approval of several transformative therapies for chronic lymphocytic leukemia, the most common leukemia in adults, led to our decision to name CLL the Advance of the Year for 2015. In addition, early promising results were reported on drugs targeting a number of rare genetic abnormalities in lung tumors. The FDA approved two first-in-class therapies, olaparib for the treatment of advanced ovarian cancer and palbociclib for the treatment of advanced breast cancer. Each of these drugs blocks a specific molecular pathway that fuels the growth of that cancer.

Another area of research pioneered at the NIH, immunotherapy, was named ASCO's Advance of the Year in the 2016 *Clinical Cancer Advances* report. In just a few short years, researchers and regulators have moved several different immunotherapy strategies from bench to bedside.

From the first astounding successes in advanced melanoma, there is now evidence that immunotherapy works against a range of cancers. Even for patients who have exhausted all traditional treatments, immunotherapy is able to halt cancer growth, often with only mild adverse effects.

As fundamental research on cancer immunotherapy intensified, clinical trials of promising approaches followed in quick succession. Two main strategies are now being explored, both achieving major success over the past year. The first involves unleashing the body's natural immune response to cancer, and the second helps the immune system find and destroy cancer cells.

Funding for the Cancer Moonshot Initiative and the Precision Medicine Initiative will help propel further innovation in both targeted therapies and immunotherapy.

Harnessing Potential: Big Data through ASCO's CancerLinQ and TAPUR

The explosion of new science, treatments and diagnostic tests make big data initiatives more important than ever so that we can quickly learn how best to apply these breakthrough treatments to the diverse U.S. population. ASCO is leading its own big data initiative with the creation of CancerLinQ, a rapid-learning data system. CancerLinQ is a powerful database made up of vast amounts of usable, searchable, real-world cancer information. This national initiative will allow users to see trends among millions of patients by analyzing cancer patient medical records, uncovering patterns that can improve patient care, and enabling doctors to compare their care against that of their peers and recommended guidelines.

CancerLinQ's innovation helps unlock knowledge from the medical records of the 97% of cancer patients not involved in clinical trials, enabling better, more data-driven decision making. Doctors deciding on treatment plans can get new insights in seconds, not years, and tailor cancer treatments to patient needs throughout the treatment process. Ultimately, the goal is to support better patient care and quality of life, incorporating both insights drawn from big data and patient-reported outcomes.

ASCO has begun to bring real-world data into clinical research with the launch of our first ever precision medicine clinical trial, Targeted Agent and Profiling Utilization Registry (TAPUR). TAPUR will offer patients with advanced cancer access to molecularly targeted cancer drugs and collect data on clinical outcomes to expand our knowledge of how to use Food and Drug Administration approved, molecularly targeted drugs to treat additional types of cancer. TAPUR (www.tapur.org) is designed to include a broader patient population than is typically enrolled in clinical trials. It will accept patients with any advanced solid tumor, multiple myeloma, or B-cell non-Hodgkin lymphoma who are no longer responding to standard anticancer treatment or for whom no acceptable treatment is available. The treating physician will select from among the seventeen TAPUR drugs a therapy that targets the identified genomic variation in their patient's tumor.

Basic and translational research supported by the NIH and the NCI is critical to ensuring that hypotheses developed using big data platforms and pragmatic clinical trials, such as ASCO's CancerLinQ and TAPUR study, can be tested and progress continues through the treatment pipeline.

***

ASCO again thanks the Subcommittee for its continued support of cancer patients in the US through funding for the NIH and the NCI. We look forward to working with all members of the subcommittee to advance US cancer research. Please contact Amanda Schwartz at Amanda.Schwartz@asco.org with any questions.

The disAbility Resource Center
of the Rappahannock Area, Inc.
409 Progress Street, Fredericksburg VA 22401
540-373-2559 (Voice) 540-373-5890 (TTY)
1-800-648-6324 (Voice or Relay) 540-373-8126 (Fax)
Website: www.cildrc.org

April 14, 2016

Debra Fults
Executive Director
disAbility Resource Center of the Rappahannock Area, Inc.

Submitted to: U.S. House Appropriations, Subcommittee on Labor, Health & Human Services, Education and Related Agencies

Regarding: Increased funding for Independent Living

I respectfully submit this written testimony to request that you increase funding in the HHS budget for Centers for Independent Living (CIL) by $200 million, for a total of $301 million for the Independent Living line item in FY 2017. This is an important opportunity for Congress to reaffirm its commitment to the more than 57 million Americans with disabilities.

The disAbility Resource Center (dRC) is one of 17 CILs in Virginia, providing services to over 2,000 people each year in the Fredericksburg Region. These services assist people in maintaining independence, contributing to the community, and avoiding costly and restrictive institution. CILs are cross-disability, non-residential, community-based, nonprofit organizations that are designed and operated by individuals with disabilities. Our organizations are unique in that they are directly governed and staffed by people with all types of disabilities, including people with mental, physical, sensory, cognitive, and developmental disabilities.

Each of the 365 federally funded centers provides five core services: information and referral, individual and systems advocacy, peer support, independent living skills training, and transition services, which were added with the passage of the Workforce Innovation and Opportunity Act (WIOA). From 2012-2014, CILs provided the core services to nearly 5 million people with disabilities, and provided additional services such as housing assistance, transportation, personal care attendants, and employment services to hundreds of thousands of individuals. During this same period, prior to transition being added as a core service, CILs transitioned 13,030 people with disabilities from nursing homes and other institutions into the community.

Transition services were added recently as a fifth core service with the passage of the Workforce Innovation and Opportunity Act and reauthorization of the Rehabilitation Act within WIOA. Transition services include transitioning individuals with significant disabilities from nursing homes and other institutions to home and community-based residences with appropriate supports and services, helping individuals with significant disabilities at risk of entering institutions to remain in the community, and assisting youth with significant disabilities transition to adult life. This core service is vital to achieving full participation for people with disabilities.

Now that transition services have been added, the need for funding is more critical than ever

Every day, CILs are fighting to ensure that people with disabilities gain and maintain control over their own lives. We know that this cannot occur when people reside in institutional settings. While opponents of

deinstitutionalization say that allowing people with disabilities to live in the community will result in harm, we know that the 13,030 people with disabilities who CILs successfully transitioned out of nursing homes and institutions across the country from 2012-2014 prove otherwise. Additionally, when services are delivered in an individual's home, the result is a tremendous cost savings to Medicaid, Medicare, and states. Community-based services enable people with disabilities to become less reliant on long-term government supports and they are significantly less expensive than nursing home placements. We are grateful that Congress demonstrated their understanding and support for community-based services when WIOA was passed and transition was added as a fifth core service.

The dRC, like many other CILs, maximizes every dollar and accomplishes its broad ranging mission with relatively little funding. CILs need additional funding to restore the devastating cuts to the Independent Living program, make up for inflation costs, and address the increased demand for independent living services. In 2016, the Independent Living Program is receiving nearly $2.5 million less in funding than it was in 2010. It is simply not possible to meet the demand for services and to effectively provide transition services without additional funding. Increased funding should be reinvested from the billions currently spent to keep people with disabilities in costly Medicaid nursing homes and institutions and out of mainstream society.

CILs play a crucial role in the lives of people with disabilities, and work tirelessly to ensure that people with disabilities have a real choice in where and how they live, work, and participate in the community. Additionally, CILs are an excellent service and a bargain for America, keeping people engaged with their communities and saving taxpayer money.

Please increase funding for Independent Living.

Thank you for the opportunity to provide this written testimony.

Bias, Lori

From: Julia Martinelli <jmartinelli@abilitysc.org>
Sent: Thursday, April 14, 2016 1:31 PM
To: Approp, LH
Subject: "FY 2017 written testimony for the record".

Name: Julia Martinelli

Title: Executive Director, disAbility Resource Center (dba) AccessAbility

I am writing to support the National Council on Independent Living's request for Congress to reaffirm your commitment to the more than 57 million Americans disabilities by increasing funding in the HHS appropriations for Centers for Independent Living (CILs). I am asking that you increase funding by $200 million, for a total of $301 million for the Independent Living line item in FY 2017.

CILs are cross-disability, non-residential, community-based, nonprofit organizations that are designed and operated by individuals with disabilities. CILs are unique in that they are directly governed and staffed by people with all types of disabilities, including people with mental, physical, sensory, cognitive, and developmental disabilities. Each of the 365 federally funded centers provides five core services: information and referral, individual and systems advocacy, peer support, independent living skills training, and transition services, which were added with the passage of the Workforce Innovation and Opportunity Act (WIOA). From 2012-2014, CILs provided the core services to nearly 5 million people with disabilities, and provided additional services such as housing assistance, transportation, personal care attendants, and employment services to hundreds of thousands of individuals. During this same period, prior to transition being added as a core service, CILs transitioned 13,030 people with disabilities from nursing homes and other institutions into the community.

Transition services were added as a fifth core service with the 2014 reauthorization of the Rehabilitation Act within the Workforce Innovation and Opportunity Act. Transition services include the transition of individuals with significant disabilities from nursing homes and other institutions to home and community-based residences with appropriate supports and services, assistance to individuals with significant disabilities at risk of entering institutions to remain in the community, and the transition of youth with significant disabilities to postsecondary life. This core service is vital to achieving full participation for people with disabilities.

Every day, CILs are fighting to ensure that people with disabilities gain and maintain control over our own lives. We know that this cannot occur when people reside in institutional settings. Opponents of deinstitutionalization say that allowing people with disabilities to live in the community will result in harm. We know that the 13,030 people with disabilities who CILs successfully transitioned out of nursing homes and institutions from 2012-2014 prove otherwise. Additionally, when services are delivered in an individual's home, the result is a tremendous cost savings to Medicaid, Medicare, and states. Community-based services enable people with disabilities to become less reliant on long-term government supports, and they are significantly less expensive than nursing home placements. We are grateful that Congress demonstrated their understanding and support for community-based services when WIOA was passed and transition was added as a fifth core service.

Since transition services were added as a core service, the need for funding is critical. Moreover, CILs need additional funding to restore the devastating cuts to the Independent Living program, make up for inflation costs, and address the increased demand for independent living services. In 2016, the Independent Living Program is receiving $2.5 million less in funding than it was in 2010. It is simply not possible to meet the increasing demand for services and effectively provide transition services without additional funding. Increased funding should be reinvested from the billions currently spent to keep people with disabilities in costly Medicaid nursing homes and institutions and out of mainstream society.

Centers for Independent Living play a crucial role in the lives of people with disabilities, and work tirelessly to ensure that people with disabilities have a real choice in where and how they live, work, and participate in the community. Additionally, CILs are an excellent service and a bargain for America, keeping people engaged with their communities and saving taxpayer money. NCIL is dedicated to increasing the availability of the invaluable and extremely cost-effective services CILs provide, and they have submitted written testimony with a similar request. I strongly support NCIL's testimony.

--
Thank You,

Julia Barrett-Martinelli
Executive Director,
AccessAbility

1929 S. Arizona Av. Ste 11
Yuma, AZ 85364

Telephone: (928) 329-6681
Fax: (928) 329-6715
TTY: (928) 782-7458
Email: Director@SMILE-AZ.ORG

Laura Duval
Executive Director
Services Maximizing Independent Living and Empowerment
DBA: SMILE

I am writing to support the National Council on Independent Living's request for Congress to reaffirm your commitment to the more than 57 million Americans disabilities by increasing funding in the HHS appropriations for Centers for Independent Living (CILs). I am asking that you increase funding by $200 million, for a total of $301 million for the Independent Living line item in FY 2017.

CILs are cross-disability, non-residential, community-based, nonprofit organizations that are designed and operated by individuals with disabilities. CILs are unique in that they are directly governed and staffed by people with all types of disabilities, including people with mental, physical, sensory, cognitive, and developmental disabilities. Each of the 365 federally funded centers provides five core services: information and referral, individual and systems advocacy, peer support, independent living skills training, and transition services, which were added with the passage of the Workforce Innovation and Opportunity Act (WIOA). From 2012-2014, CILs provided the core services to nearly 5 million people with disabilities, and provided additional services such as housing assistance, transportation, personal care attendants, and employment services to hundreds of thousands of individuals. During this same period, prior to transition being added as a core service, CILs transitioned 13,030 people with disabilities from nursing homes and other institutions into the community.

Transition services were added as a fifth core service with the 2014 reauthorization of the Rehabilitation Act within the Workforce Innovation and Opportunity Act. Transition services include the transition of individuals with significant disabilities from nursing homes and other institutions to home and community-based residences with appropriate supports and services, assistance to individuals with significant disabilities at risk of entering institutions to remain in the community, and the transition of youth with significant disabilities to postsecondary life. This core service is vital to achieving full participation for people with disabilities.

Every day, CILs are fighting to ensure that people with disabilities gain and maintain control over our own lives. We know that this cannot occur when people reside in institutional settings. Opponents of deinstitutionalization say that allowing people with disabilities to live in the community will result in harm. We know that the 13,030 people with disabilities who CILs successfully transitioned out of nursing homes and institutions

from 2012-2014 prove otherwise. Additionally, when services are delivered in an individual's home, the result is a tremendous cost savings to Medicaid, Medicare, and states. Community-based services enable people with disabilities to become less reliant on long-term government supports, and they are significantly less expensive than nursing home placements. We are grateful that Congress demonstrated their understanding and support for community-based services when WIOA was passed and transition was added as a fifth core service.

Since transition services were added as a core service, the need for funding is critical. Moreover, CILs need additional funding to restore the devastating cuts to the Independent Living program, make up for inflation costs, and address the increased demand for independent living services. In 2016, the Independent Living Program is receiving $2.5 million less in funding than it was in 2010. It is simply not possible to meet the increasing demand for services and effectively provide transition services without additional funding. Increased funding should be reinvested from the billions currently spent to keep people with disabilities in costly Medicaid nursing homes and institutions and out of mainstream society.

Centers for Independent Living play a crucial role in the lives of people with disabilities, and work tirelessly to ensure that people with disabilities have a real choice in where and how they live, work, and participate in the community. Additionally, CILs are an excellent service and a bargain for America, keeping people engaged with their communities and saving taxpayer money. NCIL is dedicated to increasing the availability of the invaluable and extremely cost-effective services CILs provide, and they have submitted written testimony with a similar request. I strongly support NCIL's testimony.

Sincerely,

Laura Duval
Executive Director

Center for Asian American Media
Latino Public Broadcasting
National Black Programming Consortium
Pacific Islanders in Communications
Vision Maker Media

Submitted to the House and the Senate Senate Appropriations Subcommittees
on Labor-HHS-Education and Related Agencies
Regarding CPB FY 2019 Advance Funding (FY 2017 appropriations bill)

April 13, 2016

The National Minority Consortia (NMC) submits this statement on fiscal year 2019 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 stories of diversity to the Nation. We bring unique voices and perspectives from America's diverse communities into all aspects of public broadcasting and other media, including content transmitted digitally over the Internet. *Our requests are two*: 1) That Congress direct CPB to meaningfully increase its commitment to diverse programming and serving underserved communities; and 2) that at least $445 million be provided in advance FY 2019 funding for CPB. We ask the Committee to:

**** Direct CPB to increase its efforts for diverse programming with a commitment for minority programming and for organizations and stations located within underserved communities.*** We urge Congress in bill and/or report language to recognize that CPB, while it has enabled diversity in public broadcasting, still has very far to go. 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.

CPB has a big responsibility with regard to diversity, yet the five NMC organizations combined receive only $6.5 million in discretionary funds from CPB, an amount less than 2% of the CPB budget. A previous amount of $7.5 million had been decreased by 10 percent in 2013 due to the sequestration and was never reinstated.

**** Provide FY 2019 advance appropriation for CPB of $445 million***, in order to develop content that reaches across traditional media boundaries, such as those separating television and radio.

While public broadcasting continues to uphold strong ethics of responsible journalism and thoughtful examination of American history, life and culture, it has not kept pace with our rapidly changing demographics. Members of minority groups continue to be underrepresented on programming and oversight levels within and in content production. This is unacceptable in America today, where minorities comprise 34.7 percent of the population. This becomes more urgent now that racial and ethnic minorities make up more than half of all children born in the United States today.

Public broadcasting has the potential to be particularly important for our growing minority and ethnic communities, especially as we transition to a broadband-enabled, 21st century workforce that relies on the skills and talent of all of our citizens. While there is a niche in the commercial broadcast and cable world for quality programming about our communities, it is in the public broadcasting sphere where minority communities and producers should have more access and capacity to produce diverse high-quality programming for national audiences. We therefore, urge Congress to insert strong language in this act to ensure that this is the case and that these opportunities are made available to minorities and other underserved communities.

About the National Minority Consortia. The NMC is made up of five separate and distinct organizations that address the need for programing that reflects American's growing ethnic and cultural diversity. With primary funding from the CPB, the NMC serves as an important component of Public Media content—on air and/or digitally. 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, we are in a position to ensure the future strength and relevance of Public Media content from and to our communities.

Each Consortia organization is engaged in cultivating ongoing relationships with the independent producer community by providing technical assistance and program funding, support and distribution. Often the funding we provide is the initial seed money for a project, that is matched by other public and private sources, providing true economic development. We also provide numerous hours of programming to individual Public Television and Radio stations—programming that is beyond the reach of most local stations. To have a real impact, we need funding that recognizes and values the full extent of minority participation in public life. Below is information regarding each of the five NMC organizations.

Center for Asian American Media (CAAM). CAAM's mission is to present stories that convey the richness and diversity of Asian American experiences to the broadest audience possible. They do this by funding, producing, distributing and exhibiting works in film, television and digital media. CAAM's award-winning public TV programs are seen by millions of viewers a year across the United States, including 47 documentary shows in the last four years. Since launching the groundbreaking Asian American anthology series *Silk Screen* (1982-1987) on PBS, CAAM has continued to bring works to millions of viewers nationwide. CAAM is widely recognized for its artistic and programmatic excellence. Films supported by CAAM include, *Jake Shimabukuro: Life on Four Strings* winner of the Gotham Audience Award and Peabody Award winner *American Revolutionary: The Evolution of Grace Lee Boggs* (2014) *by*

Grace Lee. These and other CAAM supported films have formed the canon of Asian American studies programs and virtually defined the development and evolution of a distinctive Asian American voice in the media for over three generations.

CAAM presents the annual CAAMFest (formerly known as the San Francisco International Asian American Film Festival) and distributes Asian American media to schools, libraries and colleges. CAAM's newest department, Digital Media, is becoming a respected leader in bringing innovative content and audience engagement to public media.

Latino Public Broadcasting (LPB). Latino Public Broadcasting (LPB) is the leader in the development, production, acquisition and distribution of non-commercial educational and cultural media that is representative of Latino people, or addresses issues of particular interest to Latino Americans. These programs are produced for dissemination to public broadcasting stations and other public telecommunication entities. Between 2009 and 2015, LPB programs won 85 awards, including the prestigious George Foster Peabody Award, two Emmys, two Imagen Awards and the Sundance Film Festival Award for Best Director, Documentary. In addition, LPB has been the recipient of the Norman Lear Legacy Award and the NCLR Alma Award for Special Achievement – Year in Documentaries.

Latino Public Broadcasting provides a voice to the diverse Latino community throughout the United States. Latinos have helped shape the Nation over the last 500-plus years and have become, with more than 50 million people, the largest minority group in the Nation.

National Black Programming Consortium/Black Public Media (NBPC) works to increase capacity in diverse communities to create, distribute and use public media. Throughout its history, its mission has been two-fold: building capacity in new generations of creators of social issue media and broadening the pool of stakeholders in public media institutions. NBPC is dedicated to developing black digital authorship and distributing unique stories of the black experience in the new media age. Since 1979 NBPC has invested over $7 million dollars in iconic documentary productions for public television; trained, mentored, and supported a diverse array of producers who create content about contemporary black experiences; and emerged as a leader in the evolving next-media landscape through its annual New Media Institute and New Media Institute: Africa programs. NBPC also distributes engaging content online through its social media portal BlackPublicMedia.org, an online home for enlightening black digital content and engagement.

Pacific Islanders in Communications (PIC). PIC's mission 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. In keeping with the mission, PIC helps Pacific Islander stories reach national audiences through funding support for productions, training and education, broadcast services, and community engagement. Last year alone, PIC provided 17.5 hours of Pacific Islander content to Public Media. In the past ten years, PIC has produced over 100 hours of programming for national broadcast, trained over 400 Pacific Islander filmmakers, and have had over 200 community screenings worldwide reaching more than 60,000 people in attendance. This summer, PIC will present their new, Emmy award winning, six- part series *Family Ingredients* on PBS. In the last two years PIC has had two films

in the award-winning series *Independent Lens*, *Kumu Hina* and *In Football We Trust*. PIC's seminal series *Pacific Heartbeat*, reached over 24 million households last year, and will begin its fifth season in May.

Vision Maker Media (VMM) (formerly Native American Public Telecommunications) empowers and engages Native People to tell stories. They serve Native producers and Indian country in partnership with public television and radio by working with Native producers to develop, produce and distribute educational telecommunications programs for all media including public television and public radio. Vision Maker Media supports training to increase the number of American Indians and Alaska Natives producing quality public broadcasting programs, which includes advocacy efforts promoting increased control and use of information technologies and the policies to support this control by American Indians and Alaska Natives. 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.

In the past two years, VMM has presented over 20 hours of programming to Public Media. 90% of public television stations utilized their content for programming needs. *The Medicine Game* was released in April 2015 and stations continue to use this program to inspire students, teachers and parents. Two brothers from the Onondaga Nation pursue their dreams of playing lacrosse for Syracuse University. Their dream nearly in reach, the boys are caught in a constant struggle to define their Native identity, live up to their family's expectations and balance challenges on and off the Reservation. Stories of hope, like *The Medicine Game,* can shine light in dark places, helping solve some of the toughest issues Native Americans face.

Thank you for your consideration of our recommendations. We see new opportunities to increase diversity in programming, production, audience, and employment in the new media environment, and we thank Congress for support of our work on behalf of our communities.

Stephen Gong, Center for Asian American Media, 145 9th St., Suite 350, San Francisco 94103
415-863-0814 sgong@caamedia.org; www.caamedia.org

Sandie Viquez Pedlow, Latino Public Broadcasting, 2550 N. Hollywood Way, Suite 301, Burbank, 91505
818-847-9656 Sandie.Pedlow@lpbp.org; www.lpbp.org

Leslie Fields-Cruz, National Black Programming Consortium, 68 E 131st St., 7th FL, NY, NY 10037
212-234-8200 leslie@nbpc.tv; www.blackpublicmedia.org

Leanne Ka'iulani Ferrer, Pacific Islanders in Communications, 615 Pi'ikoi St., Suite 1504, Honolulu, HI 96814
808-591-0059 lferrer@piccom.org; www.piccom.org

Shirley K. Sneve, Vision Maker Media, 1800 N 33rd St., Lincoln, NE 68503
402-472-3522 ssneve@netad.unl.edu; www.visionmakermedia.org

Ben Jauregui
Chairman
California State Independent Living Council (SILC)
Request to Increase Independent Living Funding by $200 Million

I am writing to request that Congress reaffirm its commitment to the 57-plus million Americans with disabilities. The U.S. Department of Health and Human Services reflects an appropriation of $101 million for Independent Living Programs in The Administration for Community Living's (ACL) FY 2017 budget table. I respectfully ask that you increase the Independent Living (IL) funding line item by $200 million.

CILs are nonprofit, community-based organizations, designed, governed, and operated by individuals with disabilities. The U.S. has 365 federally funded centers, each of which provides five core services: Information and Referrals, Individual and Systems Advocacy, Peer Support, Independent Living Skills Training, and Transition Services. The latter and 5th core service (Transition), was added when The Workforce Innovation and Opportunity Act (WIOA) became law in 2014.

Transition services provide individuals with significant disabilities the necessary services and supports that allow them to move from institutional settings to home and community-based alternatives. Transition services also divert individuals at risk of entering institutions so they can remain in the community. And they help youth with disabilities to successfully transition to postsecondary life. This core service is vital to achieving full participation for people with disabilities.

CILs provided core services to nearly 5 million people with disabilities from 2012 to 2014. They also provided additional services to hundreds-of-thousands of individuals so they could locate affordable and accessible housing, resolve transportation issues, find personal care assistance, and connect to employment services. During this same period - and prior to WIOA adding transition as a new (required) core service - CILs transitioned over 13,000 people from nursing homes and other institutional settings into the community. Each of these services is critical to independent living.

CILs struggle daily to help people with disabilities gain or maintain control over their own lives. Institutional settings provide neither control nor independence for the individual. Opponents of deinstitutionalization may argue that allowing people with disabilities to live in the community could result in their harm. But the 13,000 people successfully transitioned between 2012 and 2014 to community-based living, refute that idea.

There is a fiscal bonus to IL as well. Home or community-based (HCBS) long-term services and supports (LTSS) result in a tremendous cost savings to Medicaid, Medicare, and state healthcare programs. Institutional care facilities cost on average, three times as much as HCBS services and they enable people with disabilities to become less reliant on long-term public support. The California State Independent Living Council appreciates Congress demonstrating their understanding and support for community-based services by passing WIOA, which added transition services to the list of required services provided by CILs.

Because Transition Services are now required for CILs, the need for increased funding is more important than ever. CILs have experienced flat funding in several prior funding cycles and in 2016, the IL Program received $2.5 million less than it did in FY 2010. Cost of Living Adjustments (COLAs) have not countered the effect of inflationary costs or increased in population numbers. It is simply not possible to meet the increasing demand for all pre-WIOA services and also effectively provide transition services without additional funding. Funding from the billions currently spent to keep people with disabilities in costly Medicaid nursing facilities should be reinvested in CILs, in order to transition people with disabilities to community-based living.

Centers for Independent Living play a crucial role in the lives of people with disabilities; they work tirelessly to ensure they have a real choice in where and how they live, work, and participate in the community. CILs are a bargain for America. They keep people engaged in their communities and save the taxpayer money. The California State Independent Living Council is dedicated to increasing the IL network of services and supports in our state - and in our country. We offer this testimony and strongly urge Congress to request increased funding for Centers for Independent Living.

Testimony of Anthony F. (Bud) Rock
President and Chief Executive Officer, Association of Science-Technology Centers
submitted to the House Appropriations Subcommittee
on Labor, Health and Human Services, Education, and Related Agencies
April 14, 2016

Seeking Support for the Following Agencies and Programs in FY 2017:
Department of Education – 21st Century Community Learning Centers
Institute of Museum and Library Services – Office of Museum Services
National Institutes of Health – Science Education Partnership Award

Introduction

Chairman Cole, Vice Chair Womack, Ranking Member DeLauro, and Members of the Subcommittee, thank you for the opportunity to submit written testimony for the record. My name is Anthony (Bud) Rock, and I serve as the President and Chief Executive Officer of the Association of Science-Technology Centers (ASTC). My testimony today addresses the importance of science, technology, engineering, mathematics (STEM), and health education, and will focus specifically on the fiscal year (FY) 2017 budgets for offerings at three federal agencies over which your subcommittee has jurisdiction, including: (1) the 21st Century Community Learning Centers (21st CCLC) program at the Department of Education (ED), which would receive $1 billion under the President's FY 2017 request; the Office of Museum Services (OMS) at the Institute of Museum and Library Services (IMLS), which would receive $31.6 million under the President's FY 2017 request; and the Science Education Partnership Award (SEPA) program at the National Institutes of Health (NIH), which would receive $18.5 million under the President's FY 2017 request.

Our Request

On behalf of ASTC and the nearly 400 science centers and museums we represent here in the United States, I urge the Subcommittee to continue its strong support for critical STEM and health education programs within ED, IMLS, and NIH as the Labor, Health and Human Services, Education, and Related Agencies Appropriations Bill for FY 2017 moves forward. Specifically, I ask you to:

- Provide $1.3 billion for the 21st CCLC program (FY 2017 request is $1 billion) at ED;
- Provide $38.6 million for the OMS at IMLS (FY 2017 request is $31.6 million);
- Provide $20 million for the SEPA program at NIH (FY 2017 request is $18.5 million); and
- Continue to thoroughly examine any proposals that would seek to consolidate, reorganize, or eliminate federal STEM, health, and environmental education programs in an effort to ensure that stakeholder input has been sought and that proven, successful programs are maintained.

Before providing more detail about ASTC and the science center and museum field, I want to first offer a brief snapshot of these federal programs and why they are so vital to communities across the country.

Department of Education
For years, the **21st Century Community Learning Centers** program has supported the creation of community learning centers that provide academic enrichment opportunities during non-school hours for children—particularly those students who attend high-poverty and low-performing schools. The 21st CCLC program helps students meet state and local student standards in core academic subjects, such as reading and math; offers students a broad array of enrichment activities that can complement their regular academic programs; and offers literacy and other educational services to the families of participating children. ASTC members across the country have utilized 21st CCLC funding to partner with local school districts in an effort to highlight STEM in afterschool.

The President's FY 2017 budget request for the Department of Education includes $1 billion for the 21st Century Community Learning Centers program—$167 million less than the amount available for FY 2016. I encourage the Subcommittee to continue to support the program by providing $1.3 billion for FY 2017.

Institute of Museum and Library Services
IMLS is driven by its mission to inspire libraries and museums to advance innovation, lifelong learning, and cultural and civic engagement by providing leadership through research, policy development, and grant making. The agency's **Office of Museum Services** offers and administers competitive grant programs that undergo a rigorous peer review process in an effort to identify well-designed projects. Just last fall, IMLS announced new grants for 217 museum projects through the Museums for America and National Leadership Grants for Museums programs. Recipients included:

- The Discovery Center at Murfree Spring (Murfreesboro, Tennessee), which will use the funding to expand its STEAM Bus program's outreach visits to two underserved, rural elementary schools and deliver hands-on, discovery-based science lessons to grades 3-5 to address the need for substantive, informal science education in rural elementary schools and to encourage lifelong learning of STEM subjects while supporting Tennessee state curriculum standards;
- The Lehigh County Historical Society (Allentown, Pennsylvania), which will use the funding to conduct a complete inventory of the 12,500 small three-dimensional artifacts in its collection and to update catalog records following the relocation of collections and migration of associated catalog records into a new database;
- Two grants to the Yale Peabody Museum of Natural History (New Haven, Connecticut). The first will allow the museum to add a video production initiative to its free afterschool program that promotes STEM literacy, provides college preparation, promotes career awareness, and increases transferable skills development; the program serves 120 high school students each year in low performing, high-needs districts. The second will allow the museum to upgrade the storage conditions of approximately 4,700 Asian ethnographic objects to improve their preservation and access; the objects are currently stored in overcrowded conditions piled in wood cabinets; and
- Two grants to the Oakland Museum of California (Oakland, California). The first will allow the museum to create a forum for community engagement to inspire residents to consider a central cultural district for the city. The museum will lead a two-year planning

process to foster conversation about the community, its needs, and its future, resulting in a comprehensive plan for designing and executing new arts and cultural elements in the neighborhood immediately surrounding the museum. The second will allow the museum to survey representative content from eight currently inaccessible photographic collections to take steps to preserve the collections and make them more accessible to the public.

The President's FY 2017 budget request includes $31.6 million for the Office of Museum Services at the Institute of Museum and Library Services. ASTC asks the Subcommittee to provide $38.6 million—the congressionally authorized level of funding—for OMS programs for FY 2017.

National Institutes of Health

According to NIH, the goal of the **Science Education Partnership Award** program is to invest in educational activities that assist in workforce development to meet the nation's biomedical, behavioral and clinical research needs. By supporting partnerships between researchers and teachers, schools, and institutions like science centers and museums, the SEPA program provides opportunities for students from underserved communities to consider careers in research, provides teachers with professional development in science- and health-related content and teaching skills, and improves community health literacy through exhibits and programming at science centers and museums. To date, NIH has made 150 SEPA awards in 40 states—including Alabama, Arkansas, California, Connecticut, Maryland, Oklahoma, Pennsylvania, Tennessee, and Virginia—as well as in the District of Columbia and Puerto Rico.

The President's FY 2017 budget request includes $18.5 million—the same amount available for FY 2016—for SEPA. Given the program's impact and importance, I ask the Committee to continue its strong support by providing $20 million for SEPA for FY 2017.

STEM Education Consolidation and Reorganization

With regard to the federal STEM education consolidation plan first released by the Administration for FY 2014 and amended in each of the last three budget requests, I recognize the importance of creating efficiencies within the federal government whenever possible. Nevertheless, I continue to have serious concerns about a proposal that would eliminate effective programs that support informal STEM, health, and environmental learning. Integral federal investments, including the SEPA program itself, have been slated for termination in previous fiscal years. While SEPA now enjoys the support of the Administration, programs at the National Aeronautics and Space Administration and the National Oceanic and Atmospheric Administration were not as fortunate and are, once again, on the chopping block. I sincerely appreciate the Subcommittee's thoughtful consideration of the harmful effect of the proposed terminations, and ask you to remain steadfast in your support of these programs.

About ASTC and Science Centers

The Association of Science-Technology Centers is a global organization providing collective voice, professional support, and programming opportunities for science centers, museums, and related institutions, whose innovative approaches to science learning inspire people of all ages about the wonders and the meaning of science in their lives. Science centers are sites for

informal learning, and are places to discover, explore, and test ideas about science, technology, engineering, mathematics, health, and the environment. They feature interactive exhibits, hands-on science experiences for children, professional development opportunities for teachers, and educational programs for adults. In science centers, visitors become adventurous explorers who together discover answers to the myriad questions of how the world works—and why. As Members of this Subcommittee know, it is imperative that we spark an interest in STEM fields at an early age—a key role for community-based science centers and museums, who often undertake this effort with the aforementioned support from ED, IMLS, and NIH, in addition to other federal agencies.

ASTC works with science centers and museums to address critical societal issues, locally and globally, where understanding of and engagement with science are essential. As liaisons between the science community and the public, science centers are ideally positioned to heighten awareness of critical issues like agriculture, energy, the environment, infectious diseases, and space; increase understanding of—and exposure to—important and exciting new technologies; and promote meaningful exchange and debate between scientists and local communities.

ASTC now counts 651 members, including 486 operating or developing science centers and museums in 42 countries. Collectively, our institutions garner 100 million visits worldwide each year. Here in the United States alone, your constituents pass through science center doors 69 million times to participate in intriguing educational science activities and explorations of scientific phenomena.

Our centers reach a wide audience, a significant portion of which are school groups. Here in the U.S., 94% of our members offer school field trips, and we estimate that more than 13 million children attend science centers and museums as part of those groups each year. Field trips, however, are truly just the beginning of what science centers and museums contribute to our country's educational infrastructure, as: 92% offer classes and demonstrations; 90% offer school outreach programs; 76% offer workshops or institutes for teachers; 74% offer programs for home-schoolers; 67% offer programs that target adult audiences; 65% offer curriculum materials; 50% offer after-school programs; 34% offer youth employment programs; and 22% offer citizen science projects.

Conclusion

With this in mind, and while I am fully aware of the significant budget challenges that face this Subcommittee, Congress, and the nation, I hope you will continue to recognize the important educational offerings science centers and museums make available to students, families, and teachers, along with the essential federal support they receive from ED, IMLS, and NIH.

Again, I respectfully request that you provide $1.3 billion for the 21st Century Community Learning Centers program at the Department of Education; $38.6 million for the Office of Museum Services at the Institute of Museum and Library Services, and $20 million for the Science Education Partnership Awards program at the National Institutes of Health. In addition, please continue to closely examine any proposals that would seek to consolidate, reorganize, or eliminate federal STEM, health, and environmental education programs in

an effort to ensure that stakeholder input has been sought and that proven, successful programs are maintained.

Thank you once again for your strong support for America's science centers and museums—and for the opportunity to present these views. My staff and I would be happy to respond to any questions or provide additional information as needed by the Subcommittee.

AMERICAN PUBLIC HEALTH ASSOCIATION
For science. For action. For health.

Georges C. Benjamin, MD, Executive Director, American Public Health Association
Testimony submitted for the record on April 14, 2016
House Subcommittee on Labor, Health and Human Services, and Education, and Related Agencies

APHA is a diverse community of public health professionals who champion the health of all people and communities. We are pleased to submit our request to fund the Centers for Disease Control and Prevention at $7.8 billion and the Health Resources and Services Administration at $7.48 billion in FY 2017.

Centers for Disease Control and Prevention: We believe Congress should support CDC as an agency and urge a funding level of $7.8 billion in FY 2017. We are disappointed President Obama's budget request would cut CDC's program level by $194 million below FY 2016. We acknowledge that the president's budget provides increased funding for important programs and initiatives such as combating antibiotic resistance, preventing prescription drug overdose and research into the causes and prevention of gun violence. In addition, we are pleased his budget would fully allocate the Prevention and Public Health Fund for public health activities. Unfortunately, the president's budget cuts or eliminates other important programs including the REACH program, the Preventive Health and Health Services Block Grant, cancer prevention and control, immunizations and environmental health tracking and we urge you to maintain the funding for these important programs.

CDC provides the foundation for our state and local public health departments, supporting a trained workforce, laboratory capacity and public health education communications systems. It is notable that more than 70 percent of CDC's budget supports public health and

prevention activities by state and local health organizations and agencies, national public health partners and academic institutions.

CDC serves as the lead agency for bioterrorism and other public health emergency preparedness and response programs and must receive sustained support for its preparedness programs. Given the challenges of terrorism and disaster preparedness we urge you to provide adequate funding for the Public Health Emergency Preparedness grants.

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 last year's multi-state measles outbreak to pandemic flu preparedness, CDC is the nation's – and the world's – expert resouree and response center, coordinating communications and action and serving as the laboratory reference center for identifying, testing and characterizing potential agents of biological, chemical and radiological terrorism, emerging infectious diseases and other public health emergencies. States, communities and the international community rely on CDC for accurate information and direction in a crisis or outbreak.

Programs under the National Center for Chronic Disease Prevention and Health Promotion address heart disease, stroke, cancer, diabetes and arthritis that are the leading causes of death and disability in the U.S. These diseases, many of which are preventable, are also among the most costly to our health system. The center provides funding for state programs to prevent disease, conduct surveillance to collect data on disease prevalence, monitor intervention efforts and translate scientific findings into public health practice in our communities.

The National Center for Environmental Health protects public health by helping to control asthma, protect from threats associated with natural disasters and climate change, reduce,

monitor and track exposure to lead and other hazards and ensure access to safe and clean water. We urge you to support the president's request for the Climate and Health and Safe Water programs, increase funding for Childhood Lead Poisoning Prevention, Environmental Health Laboratory and Asthma programs, restore proposed cuts to the National Environmental and Public Health Tracking Network and restore funding for the Built Environment and Health program which was eliminated in 2016.

Prescription drug overdose is an ongoing public health problem in the U.S. killing more than 145,000 over the past decade. We urge you to support the president's request for increased funding to prevent and reduce prescription drug and heroin overdose deaths.

The development of antimicrobial resistance is occurring at an alarming rate and far outpacing the struggling research and development of new antibiotics. We urge you to support the president's request for the CDC Antibiotic Resistance Initiative that will expand FY 2016 healthcare-associated infections and AR prevention efforts from 25 states to up to 50 states, six large cities and Puerto Rico.

We strongly support the president's request to provide $10 million in unrestricted funding to CDC to conduct research into the causes and prevention of gun violence.

Health Resources and Services Administration: HRSA operates programs in every state and U.S. territory and has a strong history in improving the health of Americans through the delivery of quality health services and supporting a well-prepared workforce, serving people who are medically underserved or face barriers to needed care. While Congress has restored a portion of HRSA's discretionary budget authority over the past three years, funding for HRSA remains far too low – at 18 percent under the FY 2010 level – significantly limiting the agency's ability to meaningfully respond to growing or emerging health demands such as the Zika virus and the opioid epidemic, while still addressing persistent health needs. The nation faces a shortage of

health professionals, and a growing and aging population which will demand more health care. HRSA grantees are well positioned to address these issues, but additional funding is required to effectively do so.

HRSA has contributed to the decrease in infant mortality rate, a widely used indicator of the nation's health, which is now at a historic low of 5.8 deaths per 1,000 live births. People receiving care through the Ryan White HIV/AIDS Program achieve significantly higher viral suppression in comparison to the national average, which is central to preventing new HIV infections. The Title X Family Planning Program has helped prevent over 941,000 unintended pregnancies in 2014 and 1,176 cases of sexually transmitted disease-related infertility.

A strong investment from Congress is needed to build on these health improvements and pave the way for new achievements by supporting critical HRSA programs, including:

Primary Care programs support more than 9,000 health center sites in every state and U.S. territory, improving access to care for more than 22.9 million patients in geographically isolated and economically distressed communities. Close to half of these health centers serve rural populations. Health centers deliver comprehensive, cost-effective care and have demonstrated their ability to reduce the use of costlier providers of care.

Health Workforce supports the education, training, scholarship and loan repayment of a broad range of health professionals. These are the only federal programs focused on filling the gaps in the supply of health professionals, and improving the distribution and diversity of the workforce. The programs are responsive to the changing delivery systems, models of care and health care needs, and encourage collaboration between disciplines to provide effective and efficient coordinated care.

Maternal and Child Health including Title V Maternal and Child Health Block Grant, Healthy Start and others support initiatives designed to promote optimal health, reduce disparities,

combat infant mortality, prevent chronic conditions and improve access to quality health care for more than 34.3 million children, including children with special health care needs such as autism and developmental disabilities.

HIV/AIDS programs provide assistance to states and communities most severely affected by HIV/AIDS. The programs deliver comprehensive care, prescription drug assistance and support services for 512,000 people living with HIV/AIDS, nearly half of the total population living with the disease in the U.S. Additionally, the programs provide education and training for health professionals treating people with HIV/AIDS and work toward addressing the disproportionate impact of HIV/AIDS on racial and ethnic minorities.

Family Planning Title X services ensure access to a broad range of reproductive, sexual and related preventive health care for more than 4.1 million low-income women, men and adolescents. This program promotes healthy families and helps improve maternal and child health outcomes and reduce unintended pregnancies, infertility and related morbidity.

Rural Health improves access to care for people living in rural areas that experience a persistent shortage of health care services. These programs are designed to support community-based disease prevention and health promotion projects, help rural hospitals and clinics implement new technologies and strategies and build health system capacity in rural and frontier areas.

In closing, we emphasize that the public health system requires stronger financial investments at every stage. This funding makes up less than one 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 health care system. Successes in biomedical research must be translated into tangible prevention opportunities, screening programs, lifestyle and behavior changes and other population-based interventions that are effective and available for everyone so that we can meet the mounting health challenges facing our nation.

Sac and Fox Nation

920883 S. Hwy. 99 •• Building A • Stroud, OK 74079

Principal Chief KAY RHOADS
Second Chief DON W. ABNEY
Secretary MARY F. MCCORMICK
Treasurer JARED A. KING
Committee Member ROBERT E. WILLIAMSON

WRITTEN TESTIMONY OF THE HONORABLE KAY RHOADS, PRINCIPAL CHIEF
SAC AND FOX NATION
SUBMITTED TO THE HOUSE APPROPRIATIONS
SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES, EDUCATION AND RELATED AGENCIES
ON THE FY 2017 BUDGETS FOR THE BUREAU OF INDIAN AFFAIRS AND THE INDIAN HEALTH SERVICE

April 15, 2016

Chairman Cole and esteemed members of the Committee, on behalf of the Sac and Fox Nation I thank you for the opportunity to present our requests for the FY 2017 Budgets and matters for consideration for Health and Human Services and Education. The Sac and Fox Nation is home of Jim Thorpe, one of the most versatile athletes of modern sports who earned Olympic gold medals for the1912 pentathlon and decathlon.

Each of our suggestions and requests for your budgets this year is contained in more detail below. I am so pleased to be able to provide you this testimony and hope that it helps you in your many deliberations regarding the budgets for FY2017. The Sac and Fox Nation looks forward to building a positive relationship with your committee and enhancing the future of our people and our youth.

I. NATIONAL REQUESTS – EDUCATION

1. **Increase in funding directly to education departments to leave more money for programs.** The FY2017 budget identifies funding directly for education departments and this is a priority for the Sac and Fox Nation. Having direct funding for the administration would leave more money for programs which are seriously underfunded. Right now, we receive only $84,000 per year in higher education and vocational education funds. With the increase in demand among Native Students entering College, we are able to accommodate only about half of the requests we receive every year. An increase in this area and funding to leave more money in the program would be a significant benefit to

all our tribal students. With the adoption of the every student succeeds act, we are looking for more funding and more flexibility in programs that would allow us to target the best areas to put our funding on these issues.

2. **Support the President's Budget FY 2017 Funding Investing in Tribally Driven Education.** The Presidents Proposed Budget for FY2017 provides for a significant increase in funding, $450 million dollars over the amount allocated last year, for the ED's Title I Program. This program is the largest K-12 grant program serving the Tribal Youth in Communities all across the United States. We at the Sac and Fox Nation feel that approval of this funding increase is critical to provide the support that low income schools need to bring their systems and the education of our youth into the future. It is especially important to us because Oklahoma has so many rural and small schools who struggle to provide their students with books and materials let alone high speed internet or access to research systems which can be critical to a well-rounded education. There has long been a disparity between the educations these rural schools can provide students. There is no reason for that disparity to exist. Those funds will also provide for supplies, books and materials that are currently unavailable in these rural communities because of funding concerns. With such a large portion of the Tribal Youth of the United States attending rural schools it is imperative that the funding levels reflect the needs that exist today.

3. **Increase Funding to Early Development and Preschool Services.** The Budget presented by the President is bold in its provision for $350 million dollars for preschool development grants, $100 Million over the levels from FY2016. This increase is both needed and forward thinking. As it has been said over and over, the youth are our future and if we cannot provide for them we will not be able to move forward. The Sac and Fox Nation is proud to offer early childhood development and head start programs to our Tribal Children throughout our jurisdiction. However, these programs are consistently underfunded and cannot provide for all of the demands that exist. Especially in Oklahoma communities which can be very rural there are not a lot of options for preschool or early education. We are proud of our programs, but they are located in major areas like Shawnee, Norman and Cushing Oklahoma. More funding and more opportunities in this area would allow programs like ours to grow and expand to make sure that all tribal youth are being served when it comes to early education.

II. NATIONAL REQUESTS – HEALTH AND HUMAN SERVICES

1. **Authorize mandatory funding and fully fund Contract Support Costs (CSC) for IHS-** The President's FY2017 Budget proposal fully funds the estimated need for CSC for Indian Health Services at $800 million, a significant increase over the levels of funding from FY2016. The estimated increase includes funding for new and expanded contracts and compacts. The Budget also requests that CSC be reclassified to a mandatory appropriation beginning in FY 2018. We at the Sac and Fox Nation strongly urge you to consider allocating all the requested funds in this area and making these appropriations mandatory and separate in the future. Our health and the access of our Native People to health care is a serious and major concern all around Indian Country. It is always prominent for us because we have so many people in rural communities who need greater access to medical care. Fully funding contract support costs and making them mandatory serves to take pressure off Tribal Nations who have a lack of certainty in their medical services when they are not sure if the funding will be there or not. When there is certainty, it allows programs like ours to expand both services and locations to provide better care within reach of our people.

2. ***Increase Funding to Social Services in Indian Country through Health and Human Services.*** The President's FY2017 Budget provides robust funding for the desperately needed social services in Indian Country. That budget is calling for a $204 million dollar increase of the funding level from 2016. These funds are being dedicated to the most critical issues currently facing Indian Country including $916 Million for HHS's Administration for Children and Families, $231 Million for Head Start Programs (which I previously addressed), $194 Million for Tribal TANF, $55 Million for Child Support, $212 Million for Child Care Programs, $106 Million for Child Welfare Programs, $53 Million for the Administration of Native Americans, and $55 million in SAMHSA to help reduce the ever worrisome increases in suicide among native youth. There is no shortage of things to say regarding each of these issues and why increasing their funding levels is critical. However, in order to be brief, I will simply say that these main issues are the ones we deal with every day on the ground in Tribal Governments. Tribal members are in desperate need of aid in these areas just to make their lives work. Our children are a critical resource that we must protect and the great work that is done by the Administration of Children and Families and all the Indian Child Welfare departments across the Nation should be properly funded. With the expansion of Indian Child Welfare, the BIA Guidelines and possible regulations these programs are in dire need of funding to ensure that they are running at the best capacity and efficiency possible. Protecting our Native youth from birth, through school and their trying years of finding themselves and their purpose is something that is paramount in our eyes. We strongly encourage you to consider this increase and to help us fight to make sure that critical services are reaching those who are most in need.

3. **Increase the Level of Funding for Programs like the Title VI Elders Program Food Delivery.** At the Sac and Fox Nation we are seeing a great increase in the number of elders who need help getting meals. However, not all of those elders are medically homebound. Some don't have transportation or vehicles, some have issues with being able to drive properly and others are too far from the kitchens where we serve are meals. We would like an increase in funding to this program and implementation of more flexibility or another program to include increasing issues like those we are seeing. With an increase in funding to these programs, more kitchens or meals centers could be opened to provide for the care of our growing population of elders. While this may seem small compared to the other major issues we know you are dealing with, it is no small issue to us. For a lot of our elder population, who may live in rural areas or communities, a meal delivery may provide them the only opportunity with human interaction on any given day. Moreover, it allows them to have a good, nutritious meal which is not a possibility for a lot of them on their own. Our meal delivery staff is critical to the health of our elders to make sure they are eating, taking care of themselves and can get help when it is needed. In a rural community, a meal delivery could save a life.

Thank you for allowing me to submit these requests on these FY 2017 Budgets.

National
Family Planning
& Reproductive Health Association

Testimony of Clare Coleman, President & CEO
National Family Planning & Reproductive Health Association

Submitted to the House Appropriations Subcommittee on
Labor, Health and Human Services, Education, and Related Agencies

Re: Title X Family Planning Program
(Department of Health and Human Services/Office of Population Affairs)

April 15, 2016

Summary: Requesting $327 million in funding for Fiscal Year (FY) 2017 for the national family planning program (Title X of the Public Health Service Act).

My name is Clare Coleman; I'm the President & CEO of the National Family Planning & Reproductive Health Association (NFPRHA), a membership organization representing the nation's safety-net family planning providers—nurse practitioners, nurses, physicians, administrators and other key health care professionals. Many of NFPRHA's members receive federal funding from Medicaid and through Title X of the federal Public Health Service Act, the only federally funded, dedicated family planning program for the low-income and uninsured. These critical components of the nation's public health safety net are essential resources for those providing access to high-quality services in communities across the country. As the committee works on the Fiscal Year (FY) 2017 appropriations bill, NFPRHA respectfully requests that you make a

significant investment in Title X by including $327 million, which would help make progress to restore the capacity of the program to serve those in need.

NFPRHA was pleased to see that the administration acknowledged Title X's integral role in health care delivery by including $300 million for the program in the President's FY 2017 Budget Request, a $13.5 million increase over the FY 2016 appropriated level. However, that amount is insufficient to meet the well-documented demand for publicly funded family planning services. A recent analysis published in the *American Journal of Public Health* found that in order for all low-income, uninsured women of reproductive age to access family planning services, the program would need to be supported with approximately $737 million. The FY 2016 appropriated level of $286.5 million, therefore, represents only a fraction of what is needed to serve low-income, uninsured women across the country.

Even as more individuals benefit from insurance coverage through the Affordable Care Act (ACA) and as additional states expand Medicaid, the Title X network continues to play an essential role in our nation's service delivery framework. "Churning" and confidentiality issues, for example, play a role in keeping some individuals uninsured or unable to use the coverage they have for the full range of their family planning needs. More importantly, Title X-funded health centers, because of the quality and specialty care they provide, remain in demand even as low-income women gain access to health insurance. If the Massachusetts health reform experience were to prove representative of what could be expected as the ACA continues into its third full year of implementation, there will be a strong increase in demand for services at publicly funded family planning centers. According to a report by the Centers for Disease Control and Prevention (CDC), as health reform in Massachusetts expanded coverage for most people living in the state, Title X family planning health centers continued to have high volumes of patients, both insured and uninsured, and remained providers of choice for many.

The failure of states to expand Medicaid eligibility for all adults up to 138% of the federal poverty level (an income of $16,242 a year for an individual in 2016)—along with new barriers to coverage being sought by some expansion

states, such as premiums and other cost-sharing requirements—compounds the demand being placed on the Title X safety net. Currently, 19 states have not expanded their Medicaid eligibility under the ACA. Of those, only 1 state (WI) have full-benefit Medicaid eligibility for childless adults. For working parents, 16 of the 19 states have Medicaid eligibility equal to or less than 75% of FPL (an income of $8,910 a year); 12 have eligibility at or below 50% (an income of $5,940 a year). Six states have eligibility set at less than 25% of FPL—that means individuals making more than $2,970 are too "rich" for Medicaid.

Furthermore, emerging public health threats highlight the importance of the publicly funded family planning safety net and the need for robust Title X funding. The CDC recently reported a causal link between babies born with microcephaly and pregnant women infected with the Zika virus, and public health experts expect the Zika virus to continue to spread domestically. Because of the potentially devastating impact of the virus on the health of the developing fetus, it is imperative that women have the tools and resources to prevent unplanned pregnancies. In a time of public health emergency, women will turn to the Title X program for thorough counseling, risk assessment, and access to family planning services, and the program should be funded in a manner that allows the publicly funded family planning safety net to respond to this threat.

Similar to other publicly funded health programs, Title X has suffered budget cuts despite rising patient need. Between FY2010-FY2014, the Title X family planning program was cut a net $31 million (-10%). During the same period, approximately 1.1 million patients were lost from the program. These findings are very disturbing given that four in ten women who utilize a publicly funded family planning center say that it is there only source of care.

As appropriators grapple with how best to distribute limited federal resources, NFPRHA encourages the Committee to continue to prioritize investments in programs, including Title X, that are proven to save critical taxpayer dollars. Every $1 invested in publicly funded family planning services saves $7.09 in Medicaid costs associated with unplanned births. Additionally, services

provided in Title X-supported centers alone yielded $5.3 billion of the $10.5 billion in total savings for publicly funded family planning in 2010.

Moreover, appropriators should invest in programs, such as Title X, that focus on outcomes and increasing service efficiency. Title X has long set the standard for high-quality family planning and sexual health service provision and recently doubled down on its efforts to lead the field by advancing best practices for clinical care. In April 2014, the program issued "Providing Quality Family Planning Services - Recommendations of CDC and the U.S. Office of Population Affairs," that outlines the most up-to-date clinical recommendations for all providers of family planning care, including Title X-funded providers, to help define patient-centered, high-quality care in a family planning visit. Such efforts reinforce the network's dual role as safety-net providers and centers of excellence for family planning and sexual health care.

Lastly, Title X supports critical infrastructure and technology necessary for modern service delivery that are not reimbursable under Medicaid and commercial insurance. Resources for electronic health record implementation for safety-net providers—just as for others in the safety net—are necessary to help achieve the ACA goal of having a nationwide health information technology infrastructure and more coordinated models of care. Increased Title X funding is essential to help address the gap caused by the oversight in federal planning that led to most family planning health providers' ineligibility for the electronic health records (EHR) incentives available under the HITECH Act.

Millions of low-income women and men depend on the Title X program for affordable access to family planning and reproductive health services that help them stay healthy. However, politically motivated attacks are jeopardizing the Title X program's ability to help these vulnerable individuals and families. **NFPRHA urges the Committee to reverse this trend by making a significant investment in the nation's safety-net family planning health services and requests funding for Title X at $327 million in FY 2017.**

Testimony of Research!America to the House Committee on Appropriations Subcommittee on Labor, Health and Human Services, Education, and Related Agencies
Concerning FY17 Appropriations for NIH, CDC, and AHRQ
Submitted for the Record, April 14, 2016
Contact: Caitlin M. Leach, Director of Policy and Advocacy, Research!America

On behalf of Research!America, the nation's largest not for profit education and advocacy alliance working to accelerate medical progress and strengthen our nation's public health system, thank you for this opportunity to share our views on Fiscal Year 2017 (FY17) appropriations under the jurisdiction of the Subcommittee on Labor, Health and Human Services, Education, and Related Agencies.

The National Institutes of Health (NIH) drives the discovery of new treatments and cures

NIH is the world's leading funder of basic biomedical research, and Americans appreciate the value this research delivers. Since 1992, Research!America has commissioned national and state-level surveys to gauge public sentiment on issues related to health research and innovation. One of the most consistent findings over time has been Americans' support for basic research. In a survey commissioned in January 2015, 70 percent of respondents agreed that "even if it brings no immediate benefits, basic scientific research that advances the frontiers of knowledge is necessary and should be supported by the federal government."

More than 80 percent of NIH funding is awarded through almost 50,000 competitive grants to 300,000 researchers at more than 2,500 universities, medical schools, and other research institutions in every state and around the world. Research supported by NIH is typically at the early, non-commercial stages of the research pipeline; therefore, NIH funding complements critical private sector investment and development. The NIH also plays an essential role in educating and training America's future scientists and medical innovators. In 2015, NIH sponsored over 5,000 training grants and fellowships for biomedical- and health-focused graduate and medical students, postdoctoral researchers and young investigators— a pivotal investment in America's future research workforce.

We believe it is in the strategic interests of the United States to increase funding for NIH by at least 10 percent in FY17. To achieve this increase, it is crucial to continue your successful efforts to rebuild annual appropriations for NIH, growing the Institutes' base budget in FY17 by at least $2.4 billion or 5 percent after inflation is taken into account. Research!America believes this increase is merited by the magnitude of our health challenges, the cost of inaction and the extraordinary return on medical progress.

The Centers for Disease Control and Prevention (CDC) safeguards the nation's health

CDC is tasked with safeguarding the nation's health, and over the past 70 years it has worked diligently to thwart deadly outbreaks, costly pandemics and debilitating disease. Moreover, CDC plays a key role in research that leads to life-saving vaccines, bolsters defenses against bioterrorism and improves health tracking and data analytics. CDC's work has hastened many

health and safety improvements, such as lowering teen pregnancy rates, reducing deaths from motor vehicle accidents, lowering tobacco use and preventing millions of hospitalizations.

Ebola, Zika, Dengue fever and other emerging health threats have shown just how critical CDC is to our nation, and have also revealed the enormity of the challenge the agency faces as it works to safeguard American lives. To protect Americans, CDC needs to have a global reach; 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 FY17 to carry out its crucially important responsibilities.

AHRQ maximizes the return on medical progress

AHRQ is the lead federal agency responsible for ensuring medical progress translates into better patient care. Medical discovery, development and delivery are intertwined: the value of discovery and development hinge on smart health care delivery. That's where AHRQ comes in. AHRQ-funded research is used to ensure patients receive the right care at the right time in the right settings. This research serves many critical purposes, from ensuring information about new medical discoveries reaches doctors and patients as quickly as possible, to deploying health IT to address challenges in health care access and delivery, to cutting the number of deadly – and preventable – medical errors.

If we underinvest in AHRQ, we are inviting unnecessary health care spending and squandering the opportunity to ensure patients receive the quality care they need. We ask that you commit to investing in life and cost-saving health services research by funding AHRQ at $364 million in FY17.

Conclusion

There are few federal investments that convey benefits as important and far-reaching as funding for NIH, CDC and AHRQ: new cures, new businesses, new jobs; innovative solutions that improve health care delivery and optimize the use of limited health dollars; and a public health system nimble and sophisticated enough to meet daunting challenges to the health and safety of the American people. We appreciate your consideration of our funding requests and thank you for your stewardship over such critically important federal spending priorities.

Written Testimony for the Record to the House Subcommittee on Labor, Health and Human Services, Education and Related Agencies regarding FY 2017 Appropriations for HIV/AIDS Programs Submitted by Dr. Carlos del Rio, FIDSA, on behalf of the HIV Medicine Association (HIVMA) April 14, 2016

The HIV Medicine Association (HIVMA) of the Infectious Diseases Society of America (IDSA) represents more than 5,000 physicians, scientists and other health care professionals who practice on the frontlines of the HIV/AIDS pandemic. Our members provide medical care and treatment to people with HIV/AIDS in the U.S. and globally, lead HIV prevention programs and conduct research that has led to the development of effective HIV prevention and treatment options. As you work on the FY2017 appropriations process, we urge you **to invest in the medical research supported by the National Institutes of Health (NIH),** sustain robust funding for **the Ryan White Program at the Health Resources and Services and Administration (HRSA)** and support adequate funding for the **Centers for Disease Control and Prevention's (CDC) HIV and STD prevention programs.**

Early access to effective HIV treatment helps patients with HIV live healthy and productive lives and is cost effective.[1] Treatment not only saves the lives of individuals with HIV but directly benefits public health by reducing HIV transmission risk to near zero.[2] However, despite our remarkable progress in HIV prevention, diagnosis and treatment, the HIV/AIDS epidemic is far from over. HIV/AIDS continues to pose a serious disease burden and public health threat in the United States with more than 1.2 million people living with HIV infection. Almost 1 in 8 (12.8%) individuals living with HIV are not aware of their HIV infection and there are an estimated 50,000 new infections occurring annually in the U.S. In our country, HIV infection disproportionately impacts racial and ethnic minority communities and low income people who depend on public services for their life-saving health care and treatment. The rate of new HIV infection in African Americans is 8 times that of whites.[3] Globally, there are more than 35.3 million people living with HIV, the great majority of them in Sub-Saharan Africa.

The funding requests in our testimony largely reflect the consensus of the Federal AIDS Policy Partnership (FAPP), a coalition of HIV organizations from across the country, and are estimated to be the amounts necessary to mount an effective response to the domestic HIV epidemic and meet the need in communities across the country.

NIH – Office of AIDS Research (OAR): HIVMA strongly supports an overall FY2017 budget request level of at least $34.5 billion for the NIH, and urges that at least $3.45 billion be allocated to the NIH Office of AIDS Research. This level of funding is vital to sustain the pace of research that will improve the health and quality of life for millions of people in the U.S. and in the developing world. Flat funding of HIV/AIDS research since FY2015 threatens to slow progress toward a vaccine and a cure, erode our capacity to sustain our nation's historic worldwide leadership in HIV/AIDS research and innovation, and discourage the next generation of scientists from entering the field.

Our past investment in HIV/AIDS research paid off in dramatic reductions in mortality from AIDS of nearly 80 percent in the U.S. and in other countries where treatment is available. This research also helped reduce the mother to child HIV transmission rate from 25 percent to less than 1 percent in the U.S. and to very low levels in other countries where treatment is available. Sustained investments in NIH funding are also essential to train the next generation of scientists and prepare them to make tomorrow's HIV discoveries.

The NIH-Wide Strategic Plan[4] identifies criteria for setting the NIH's research priorities, including consideration of the value of permanently eradicating a disease – noting that biomedical research stands at another such pivotal moment today: the very real possibility of entirely eliminating HIV/AIDS. The plan also notes that such an investment makes good economic sense: every new case of HIV diagnosed in the United States translates into a lifetime cost of approximately $350,000 for treatment with antiretroviral drugs. Getting to zero new cases of HIV/AIDS would save our nation an estimated $17.5 billion annually.[5] Congress should ensure our nation does not delay vital HIV/AIDS research progress.

HRSA – HIV/AIDS Bureau (HAB): At this critical time in the HIV/AIDS epidemic, when research has confirmed that early access to HIV care and treatment not only saves lives but prevents new infections by reducing the risk of transmission to near zero for patients who are virally suppressed and keeps patients engaged and working, it is essential to maintain overall funding levels for the Ryan White Program. Increasing access to and successful engagement in effective, comprehensive HIV care and treatment is the only way to lead the nation to an AIDS-free generation and reduce the devastating costs of – including lives lost to – HIV infection. The Ryan White Program annually serves more than half a million individuals living with HIV in the U.S., providing the care and treatment that allows them to live close to a normal lifespan. HIVMA urges an allocation of $225.1 million, or a $20 million increase, for Ryan White Part C programs in FY 17. Part C-funded HIV medical clinics currently struggle to meet the demand of increasing patient caseloads. The expert, comprehensive HIV care model or "medical home" that is supported by the Ryan White Program has been highly successful at achieving positive clinical outcomes with a complex patient population. Patients with HIV who receive Ryan White services are more likely to be prescribed HIV treatment and to be virally suppressed.[6] ***We also know that the annual health care costs for HIV patients who are not able to achieve viral suppression (often due to delayed diagnosis and care) are nearly 2.5 times that of healthier HIV patients.***[7]

While the Affordable Care Act (ACA) provides important new health care coverage options for many patients, most health insurers fail to support the comprehensive care and treatment necessary for many patients to manage HIV infection. High cost sharing, benefit gaps and limited state uptake of the Medicaid expansion, especially in the South, necessitate an essential and ongoing role for the Ryan White Program to avoid life-threatening and costly disruptions in care.

HIVMA does not support the proposal to consolidate Ryan White Part D funding into Part C. Ryan White Part C and D programs both provide comprehensive, effective care and treatment for women, infants, children and youth living with HIV/AIDS. Part D programs have cultivated special expertise for engaging and retaining women, including pregnant women, HIV-exposed infants, and young people in care. The programs provide services tailored to women and young people and in some communities, Part D-funded programs are the main providers of HIV care and treatment.

Additionally, we support the President's request to increase by $9 million the Special Projects of National Significance in order to increase hepatitis C virus (HCV) testing, and care and treatment for people living with HIV who are co-infected with HCV.

CDC - National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention (NCHHSTP): HIVMA appreciates the much needed increase of $5 million proposed in the President's FY2017 budget for the CDC's NCHHSTP, to be directed to **viral hepatitis – however, an increase on the order of $30 million**

would more adequately meet the urgent need to ramp up the national response to the burgeoning viral hepatitis epidemic which has been fueled by injection drug use in the wake of the opioid and heroin addiction crisis. We also support sustained funding for HIV and STD prevention and surveillance, plus **the Division of Adolescent School Health (DASH). We are also especially concerned about flat funding of CDC's global HIV programs, and request an increase of at least $3.3 million for a total of $132 million, which includes resources for the agency's essential role in implementing PEPFAR programs in developing nations.**

Policy Riders – Continue Progress on Federal Funding for Syringe Exchange Programs:
HIVMA applauds the subcommittee's work in advancing report language that allows for the judicious use of federal funding for syringe exchange programs (SEPs) as an important prevention and public health intervention. We support the continuation of this policy. SEPs are associated with decreases in HIV and viral hepatitis incidence, and provide an important point of healthcare access, including initiation of HIV and viral hepatitis education, counseling and testing, linkage to care, and entry into substance use treatment. SEPs also benefit community safety by reducing the number of improperly disposed syringes as well as reducing needle stick injuries to law enforcement officers and other first responders.

Conclusion: We are at serious risk of losing ground against the HIV pandemic if we fail to prioritize HIV public health, treatment and research programs. HIV remains the leading infectious killer worldwide, and we must fully leverage and invest in HIV prevention, care and treatment and research to save the lives of millions who are infected or at risk of infection here in the U.S. and around the globe, and ultimately to end the HIV/AIDS epidemic.

---

[1] Kitahata, Gange, Abraham, et al. Effect of early versus deferred antiretroviral therapy for HIV on survival. New Engl J Med 2009;360:181S-26.
[2] Cohen, Myron S., et al. Prevention of HIV-1 Infection with Early Antiretroviral Therapy. 2011 New England Journal of Medicine 493-505: V365, no 6, http://www.nejm.org/doi/full/10.1056/NEJMoa1105243
[3] CDC Fact Sheet, February, 2014, accessed online at: http://www.cdc.gov/hiv/risk/racialethnic/aa/facts/index.html
[4] *NIH-Wide Strategic Plan, Fiscal Years 2016–2020: Turning Discovery Into Health*, (December, 2015).
[5] Ibid, p. 32.
[6] Bradley, H., et al. Ryan White HIV/AIDS Program Assistance and HIV Treatment Outcomes in the United States. CROI 2015. Abstract: 1064. Accessed online at: http://www.croiconference.org/sessions/ryan-white-hivaids-program-assistance-and-hiv-treatment-outcomes-united-states.
[7] Based on data from Gilman BH, Green, JC. Understanding the variation in costs among HIV primary care providers. AIDS Care.2008:20;1050–6.

Statement of Michael Riksen
Vice President – Policy & Representation, National Public Radio
Before the Subcommittee on Labor, Health and Human Services, Education and Related Agencies, U.S. House Committee on Appropriations

April 15, 2016

Dear Chairman Cole, Representative DeLauro and Members of the Subcommittee,

Thank you for this opportunity to urge the Subcommittee's support for an annual federal investment of $445 million to public broadcasting through the Corporation for Public Broadcasting, (CPB) for Fiscal Year (FY) 2019. Public radio joins with our public television partners in urging the Subcommittee's support for $50 million in FY 2017 for the second year of a multi-year request to upgrade interconnection for the public broadcasting system. With your support, and these essential funds, every American will continue to have free access to the best in public service journalism, music, news, educational, entertainment and cultural programming.

I offer this testimony on behalf of the public radio system, a uniquely American public service, non-for-profit media enterprise that includes NPR, our more than 950 independently owned local member stations, other producers and distributors of public radio programming including American Public Media (APM), Public Radio International (PRI), the Public Radio Exchange (PRX), and many stations, both large and small, rural and urban, that create and distribute content through the Public Radio Satellite System (PRSS).

The annual demonstration of support by Congress to CPB helps to sustain and enhance a system that is wholly representative of its users in our country. While just a tiny fraction (0.01%) of the entire federal budget goes to CPB, you help support one of America's most vibrant and successful community-centric programs. With the money provided by Congress, local stations are able to raise $6 for every federal grant dollar they are awarded. This federal financial investment permits local stations to invest more deeply in their own local news and cultural programming and participate in CPB-backed regional news collaborations with stations across the country. This in turn enables our stations to provide the American public with an enduring and daily return on investment that is heard, seen, read, and experienced in public radio broadcasts, apps, podcasts, and on online.

With support from CPB's community service grants, each of the hundreds of independently operated public radio stations is responsible for curating and creating the mix of programs that best addresses the needs of their local community. Local stations and their programming choices are as diverse as the people who live in the communities they serve. Some have all-news formats. Others have all-music formats and still other blend news, talk, commentary and music into their program offerings. Close to thirty percent of our stations' daily programming is locally generated. Every year the federal government invests roughly $90

million dollars in the operation of America's local public radio stations. And these stations provide service to all of America's communities.

Each public radio station operates autonomously, but they are all interconnected through a single satellite service that allows Americans to receive free and universal access to a wide array of content and services from local, national and international reporters and producers. The Public Radio Satellite System reaches 95% of the U.S. population, making a community's local station the single most reliable source for public safety information in an emergency or natural disaster situation. PRSS fulfills an important mission by providing a common, shared platform for secure, reliable, cost-effective and efficient distribution of all public radio content including news, music, cultural, educational and entertainment programming to almost 1,600 stations across the country that serve an increasingly diverse population. As part of that mission, the PRSS provides satellite transmission services to distribute programming that reaches under-served audiences and rural areas.

With the combined strength of public radio's role as a trusted media and information resource and the interconnected of the PRSS serving as an essential public-safety asset, U.S. consumers are urging the mobile phone industry to install and activate FM chips in all cellphones and smart phones. During every hurricane, tornado, flood, earthquake, blizzard and wildfire, local public radio stations play an essential role in conveying information about response efforts, local relief supplies, evacuation orders, emergency routs and where to find food, shelter and fuel, as well as on-the-ground, and at-the-scene reporting to help affected communities understand and respond. Now is the time for major cell carriers and manufacturers to activate FM chips in their mobile devices.

Our overarching goal is to ensure that we are serving our audience wherever they are, and however they are finding us, with exceptional journalism, balancing the needs of our traditional broadcast listeners with those whose connection to public radio's work is through our many digital platforms. With more than 1,400 journalists in nearly 200 newsrooms across America, public radio is already an essential part of people's lives. The opportunity now is to share expertise between our journalists to make our local, regional and national stories even better. Collaborative reporting helps local stories spread national and give national stories unique local perspective by leveraging the ideas, the money and the system that are already in place. For example, the CPB supported New England News Collaborative (NENC) will produce multimedia coverage focusing on the region's energy usage, climate, transportation infrastructure, and its people and immigration issues. This robust partnership will produce dynamic reporting projects for on-air broadcast, digital and web presentations, and a series of public Town Hall-style meetings designed to discuss and debate the issues facing New England and its residents.

Public radio's culture of innovation is evident in the system's commitment to the news collaborations. The base of public radio's efforts to improve news collaboration are strengthened

by NPR One, the audio app that connects listeners to a stream of public radio news, stories and podcasts curated for the listener. A service that is not provided anywhere else- making news and information accessible for all citizens via mobile device. News of the listener's community is seamlessly woven into the listening experience, informing, engaging, inspiring and surprising. This creates access for an individual to be informed and up to date at all times, whether they have a transistor radio available or not.

To provide some examples of the great local service provided throughout Oklahoma Mr. Chairman, this fall is the 20th anniversary of KGOU's change to news and information during the weekdays. Since the change, the service area has expanded greatly in to Ada, Seminole, Chickasha, Shawnee and Woodward Native areas. *Invisible Nations*, explores the modern Native culture in Oklahoma. Pivoting stories and reporting about Native America away from tragedy, loss and hardship and providing public media audiences with the complex and rich stories of our nation's First People. KGOU is also utilizing their proximity to the University of Oklahoma though the student produced public affairs program. Each semester, University students produce programs at the station. Public radio gives students the chance to work on real news stories from investigative journalism to editing to recording on-air stories.

By broadcasting exemplary news, local reporting, classical music, and cultural programming in Connecticut, Congresswoman DeLauro, WSHU strives to foster intelligent discourse, contribute to an informed electorate, preserve an important part of the culture and, allow listeners to make informed decisions about their daily lives. As a member of the New England news Collaborative, WSHU shares the responsibility of providing multiplatform journalism, including broadcast, digital and town-hall meetings about issues facing New Englanders. Over three decades of ever-expanding service to its communities, the station has consistently delivered international and national news and information through its growing cadre of community-based reporters as well as music programming that supports and enhances the important work of the region's music ensembles, teachers and artists. WSHU strives to bring the community the regional news that directly affects their life every day, with the hope that listeners will learn something new about their world and understand why it happened. Keeping listeners informed by closely monitoring state legislation, regional elections, local business, current events and cultural happenings.

Federal funding for public broadcasting is a small investment that pays big dividends. And when it comes to music, public radio plays a unique and critically important role. We have created a value partnership that connects music and those who devote their lives to it from artists, performers and composers to audiences. Our local stations play a significant role in music discovery, preservation, education, diversification and local music economies. And this role is enabled by CPB's community service grants to local public radio stations.

Nationally, more than 400 public radio stations have full-time music formats and an additional 747 play music as part of their programming lineups. Local public radio stations air

more than 5.6 million hours of music per year, the majority of which is local programming. In addition to prerecorded music, member stations host more than 10,000 in-studio and community-based performances.

With music platforms changing so dramatically in the last ten years, public radio provides a home for genres that are economically unsustainable in the commercial market, including classical, jazz, folk, opera and traditional regional music such as bluegrass and zydeco. In fact, over 90% of all broadcast classical music in America is available only on public radio, and the same is quickly becoming true for jazz. Our stations help support and preserve cultural institutions, including local bands, symphony orchestras, philharmonic societies, theater groups, and historical venues. Public radio's role in music is not possible without a diverse revenue base, including CPB's financial support to local stations.

Mr. Chairman and Representative DeLauro, NPR and the public radio system are committed to being America's public radio where rationale, fact-based, accurate and civil reporting and conversation are our top priorities. We have no political agenda and we do not take sides. Public radio plays an important, significant and growing role in news, journalism, talk and music/cultural programming across all age groups. Our stations are essential to, and part of, the communities they serve.

Through news, talk, music and cultural programming, public radio stations are reaching out to audiences wherever they are with the content their audience wants. We're embracing America's changing demographics and using digital media and news collaborations to connect better, more quickly and in more diverse ways. Today's public radio isn't going away, it's going everywhere and we are working every day to earn the trust of the 38 million Americans who rely on us for news and insights that guide and inform.

Usher Syndrome Coalition
2 Clock Tower Place, Suite 418
Maynard, MA 01754
(o) 978.637.2625 | (f) 978.637.2618
www.usher-syndrome.org

USHER SYNDROME COALITION

Written Testimony of Carmen Marottolo, Jr. of Durham, Connecticut
Labor, Health and Human Services, Education, and Related Agencies
Subcommittee of the House Committee on Appropriations
April 15, 2016

My name is Carmen Marottolo, Jr. and I have Usher syndrome, the most common genetic cause of combined deafness and blindness. I write on behalf of the Usher syndrome community to urge this committee to support the inclusion of report language prioritizing research into the treatment of Usher syndrome at the National Institutes of Health (NIH).

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

As you prepare the Fiscal Year 2017 Labor, Health and Human Services, Education bill, we respectfully request that you include the following report language with the objective of better defining the plan and measurements for the delivery of vision loss treatments for those with Usher syndrome:

> *Usher syndrome - The Committee continues to urge the NIH to prioritize Usher syndrome research at NEI and NIDCD. The Committee requests an update in the fiscal year 2017 budget request on steps NIH has taken to date and future plans to accelerate treatment options and improve patient outcomes for those with Usher syndrome. The update should include a description of the criteria in use by NIH to evaluate Usher syndrome related grant submissions to ensure the prioritization of those that accelerate human treatment*

options. The update should also include a timeline and deliverables that will be used to evaluate the progress made towards viable treatments for those with Usher syndrome.

In the United States, it is estimated that nearly 50,000 people have this rare genetic disorder. This devastating and life changing condition has a similar affect on all of us with Usher and on our families. But, we all have different stories to tell.

This is my story. I was born on July 31, 1960 in New Haven, Connecticut. My mother is an Irish/German American and my father is an Italian American. I was raised with Catholic beliefs and in a loving home. My parents have five children: two girls and three boys. As difficult as it was being young parents, they discovered their first three children had hearing losses. Doctors used to say, it's very rare to have three children in the same family with a hearing loss. There was no mention of Usher syndrome at that time.

I am a firm believer that learning starts at home. My parents gave us opportunities and encouraged us to be productive members of society. This is what built my character for a good work ethic and to become independent with strong family values.

This is my basic timeline: at age four, my parents realized I had a hearing loss (as well as my two sisters) but did not know I had a serious vision problem. My hearing loss was corrected with amplification. I managed very well with hearing aids through my school years. It did not stop me from doing the things I loved, playing sports and being involved in community activities.

At 6 feet and 200lbs, I enjoyed playing and watching basketball. At age 20, I noticed I was having some difficulties seeing people standing right next to me or on a basketball court. I couldn't see a ball that was passed to me. This is when I was first told about Usher syndrome.

I had no peripheral vision but very good central vision. Well, that explained why I would stumble or bump into objects or people. As determined as I am, I continue to lead a "normal" life. I graduated from Southern CT State University with a B.S. degree in 1982.Two years later, I got married and had a son.

In 1986, I was hired by the United States Postal Service as a Mail handler. My life was simple and productive until 2013. My employer (U.S.P.S.) noticed a change in my vision. It became evident that I was struggling with my central vision. At age 53, after working 27 years, I am now in a life-changing situation, struggling with my vision loss and with an employer who says I'm not safe to perform my duties.

I have received several letters of commendations for exceptional work performance. And now I'm being told I can't do my job. I was devastated! Angry? That's an understatement. I was determined to win my job back and to prove my ability, with help from the Bureau of Vocational Rehabilitation in Connecticut, an organization for people with visual impairment.

I fought hard to reassure my employer that I can continue working and to be able to retire respectfully. After six months of an endless battle, I was allowed to continue working. I am presently on course to retire in August 2016.

Some people will say it was a victory for me to get the 30 years of service, but I do not want to retire. I love my job and I wanted to continue being a proud member of the workforce. My vision has deteriorated so rapidly in the past couple of years, it's just not safe anymore.

People with Usher syndrome share the same range of intelligence and work ethic as any American. Yet they suffer from an 82% unemployment rate. People with Usher syndrome are born with the same emotional strength as any other. Yet they have a suicide rate that is 2 ½ times greater than the general population. People with Usher syndrome not only have the capacity to

contribute to America's future, they thirst for it. They want to be active members of society. Yet our country spends an estimated $139 billion annually in direct and indirect costs for people with eye disorders and vision loss. That doesn't even include the costs associated with hearing impairment.

Now, at age 55, I have no vision in my right eye and very limited in my left eye. My left eye was my saving grace, until recently. I see haziness and dark shadows. I have NO face recognition. Last night, sitting at a local restaurant with friends and family, I could not see one face. That's not "normal". I just smiled and laughed but I felt all alone inside. Sometimes I feel like I'm the only one in the world with a vision loss. Depressing? Frustrating? Of course! As mentioned before, people with Usher syndrome all have similar challenges. Everyday I deal with a new challenge. Things most people take for granted; sweeping the garage, trying to find a tool, or just simply watching TV. It becomes mentally and sometimes physically exhausting.

Until very recently, there was no way of knowing how much money NIH invested in Usher syndrome research. Through the efforts of the Usher Syndrome Coalition, this rare disease has been added as a new category in the NIH Categorical Spending list, the Estimates of Funding for Various Research, Condition, and Disease Categories (RCDC). Through the RCDC system, we now have visibility into the total dollars spent on Usher syndrome, as well as the specific grants that were funded. More important to us than increasing the dollars invested in Usher syndrome research is ensuring those dollars are invested in the most impactful manner.

We would like to see a strategic plan put forth by the National Institutes of Health developed with both internal and external expertise containing clear measurements of progress. NIH investment should target those research areas that will most quickly bring about viable human treatments for the vision loss phenotype in Usher syndrome. There are technologies and

techniques available today to manage the hearing loss and vestibular issues faced by those with Usher syndrome. These are not perfect and more investment is needed, but the priority should be to provide treatments that allow people with Usher syndrome to manage the vision loss as well as they currently manage the hearing and vestibular losses.

The dollars invested in Usher syndrome research are precious to all of us. We want to make sure they are spent as wisely as possible. As for me, I will keep pushing forward and continue to fight. I always say: I do not want sympathy, just a little understanding.

Thank you for reading my story.

Best regards,

Carmen Marottolo, Jr.

Kat Lyons
Advocacy Coordinator
Center for Independent Living Options
Cincinnati, OH

I am writing to support the National Council on Independent Living's request for Congress to reaffirm your commitment to the more than 57 million Americans disabilities by increasing funding in the HHS appropriations for Centers for Independent Living (CILs). I am asking that you increase funding by $200 million, for a total of $301 million for the Independent Living line item in FY 2017.

CILs are cross-disability, non-residential, community-based, nonprofit organizations that are designed and operated by individuals with disabilities. CILs are unique in that they are directly governed and staffed by people with all types of disabilities, including people with mental, physical, sensory, cognitive, and developmental disabilities. Each of the 365 federally funded centers provides five core services: information and referral, individual and systems advocacy, peer support, independent living skills training, and transition services, which were added with the passage of the Workforce Innovation and Opportunity Act (WIOA). From 2012-2014, CILs provided the core services to nearly 5 million people with disabilities, and provided additional services such as housing assistance, transportation, personal care attendants, and employment services to hundreds of thousands of individuals. During this same period, prior to transition being added as a core service, CILs transitioned 13,030 people with disabilities from nursing homes and other institutions into the community.

Transition services were added as a fifth core service with the 2014 reauthorization of the Rehabilitation Act within the Workforce Innovation and Opportunity Act. Transition services include the transition of individuals with significant disabilities from nursing homes and other institutions to home and community-based residences with appropriate supports and services, assistance to individuals with significant disabilities at risk of entering institutions to remain in the community, and the transition of youth with significant disabilities to postsecondary life. This core service is vital to achieving full participation for people with disabilities.

Every day, CILs are fighting to ensure that people with disabilities gain and maintain control over our own lives. We know that this cannot occur when people reside in institutional settings. Opponents of deinstitutionalization say that allowing people with disabilities to live in the community will result in harm. We know that the 13,030 people with disabilities who CILs successfully transitioned out of nursing homes and institutions from 2012-2014 prove otherwise. Additionally, when services are delivered in an individual's home, the result is a tremendous cost savings to Medicaid, Medicare, and states. Community-based services enable people with disabilities to become less reliant on long-term government supports, and they are significantly less expensive than nursing home placements. We are grateful that Congress demonstrated their understanding and support for community-based services when WIOA was passed and transition was added as a fifth core service.

Since transition services were added as a core service, the need for funding is critical. Moreover, CILs need additional funding to restore the devastating cuts to the Independent Living program, make up for inflation costs, and address the increased demand for independent living services. In 2016, the Independent Living Program is receiving $2.5 million less in funding than it was in 2010. It is simply not possible to meet the increasing demand for services and effectively provide transition services without additional funding. Increased funding should be reinvested from the billions currently spent to keep people with disabilities in costly Medicaid nursing homes and institutions and out of mainstream society.

Centers for Independent Living play a crucial role in the lives of people with disabilities, and work tirelessly to ensure that people with disabilities have a real choice in where and how they live, work, and participate in the community. Additionally, CILs are an excellent service and a bargain for America, keeping people engaged with their communities and saving taxpayer money. NCIL is dedicated to increasing the availability of the invaluable and extremely cost-effective services CILs provide, and they have submitted written testimony with a similar request. I strongly support NCIL's testimony.

Tiffany Hovelson

Independent Living Advocate

Freedom Resource Center for Independent Living

I am writing to support the National Council on Independent Living's request for Congress to reaffirm your commitment to the more than 57 million Americans with disabilities by increasing funding in the HHS appropriations for Centers for Independent Living (CILs). I am asking that you increase funding by $200 million, for a total of $301 million for the Independent Living line item in FY 2017.

CILs are cross-disability, non-residential, community-based, nonprofit organizations that are designed and operated by individuals with disabilities. CILs are unique in that they are directly governed and staffed by people with all types of disabilities, including people with mental, physical, sensory, cognitive, and developmental disabilities. Each of the 365 federally funded centers provides five core services: information and referral, individual and systems advocacy, peer support, independent living skills training, and transition services, which were added with the passage of the Workforce Innovation and Opportunity Act (WIOA). From 2012-2014, CILs provided the core services to nearly 5 million people with disabilities, and provided additional services such as housing assistance, transportation, personal care attendants, and employment services to hundreds of thousands of individuals. During this same period, prior to transition being added as a core service, CILs transitioned 13,030 people with disabilities from nursing homes and other institutions into the community.

Transition services were added as a fifth core service with the 2014 reauthorization of the Rehabilitation Act within the Workforce Innovation and Opportunity Act. Transition services include the transition of individuals with significant disabilities from nursing homes and other institutions to home and community-based residences with appropriate supports and services, assistance to individuals with significant disabilities at risk of entering institutions to remain in the community, and the transition of youth with significant disabilities to postsecondary life. This core service is vital to achieving full participation for people with disabilities.

Every day, CILs are fighting to ensure that people with disabilities gain and maintain control over our own lives. We know that this cannot occur when people reside in institutional settings. Opponents of deinstitutionalization say that allowing people with disabilities to live in the community will result in harm. We know that the 13,030 people with disabilities who CILs successfully transitioned out of nursing homes and institutions from 2012-2014 prove otherwise. Additionally, when services are delivered in an individual's home, the result is a tremendous cost savings to Medicaid, Medicare, and states. Community-based services enable people with disabilities to become less reliant on long-term government supports, and they are significantly less expensive than nursing home placements. We are grateful that Congress demonstrated their understanding and support for community-based services when WIOA was passed and transition was added as a fifth core service.

Since transition services were added as a core service, the need for funding is critical. Moreover, CILs need additional funding to restore the devastating cuts to the Independent Living program, make up for inflation costs, and address the increased demand for independent living services. In

2016, the Independent Living Program is receiving $2.5 million less in funding than it was in 2010. It is simply not possible to meet the increasing demand for services and effectively provide transition services without additional funding. Increased funding should be reinvested from the billions currently spent to keep people with disabilities in costly Medicaid nursing homes and institutions and out of mainstream society.

Centers for Independent Living play a crucial role in the lives of people with disabilities, and work tirelessly to ensure that people with disabilities have a real choice in where and how they live, work, and participate in the community. Additionally, CILs are an excellent service and a bargain for America, keeping people engaged with their communities and saving taxpayer money. NCIL is dedicated to increasing the availability of the invaluable and extremely cost-effective services CILs provide, and they have submitted written testimony with a similar request. I strongly support NCIL's testimony.

STATEMENT ON AMYLOIDOSIS

BY
ANN D. PEEL
PRIVATE CITIZEN, BETHESDA, MARYLAND

SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES, EDUCATION AND RELATED AGENCIES
COMMITTEE ON APPROPRIATIONS
U.S. HOUSE OF REPRESENTATIVES

APRIL 15, 2016

Mr. Chairman,

Amyloidosis is a rare and often fatal disease. I ask that you include language in the Committee's report for fiscal year 2017 recommending that the National Institutes of Health (NIH) expand its research efforts into amyloidosis, a rare disease characterized by abnormally folded protein deposits in tissues. I also request that the report language for fiscal 2017 directs NIH to keep the Committee informed on the steps taken to increase the understanding of the causes of amyloidosis and the measures taken to improve the diagnosis and treatment of this devastating group of diseases.

There is no known cure for amyloidosis. Current methods of treatment are risky and unsuitable for many patients. I have endured two stem cell transplants in order to fight the deadly disease amyloidosis and have survived the disease for 13 years due to the intensive, life-saving treatment that I have received. I want to use my experience with this rare disease to help save the lives of others.

Amyloidosis can cause heart, kidney, or liver dysfunction and failure and severe neurologic problems. Left untreated, the average survival is about 15 months from the time of diagnosis. Amyloidosis can literally kill people before they even know that they have the disease.

More research needs to be funded for various types of amyloidosis. Researchers have not been able to determine the root cause of the disease or an effective low-risk treatment. The patients with amyloidosis who are able to obtain treatment face challenges that can include high dose chemotherapy and stem cell transplantation or organ transplantation.

Amyloidosis is vastly under-diagnosed. Thousands of people die because they were diagnosed too late to obtain effective treatment. Thousands of others die never knowing they had amyloidosis.

AMYLOIDOSIS

Amyloidosis occurs when unfolded or misfolded proteins form amyloid fibrils and are deposited in organs, such as the heart, kidney and liver. These misfolded proteins clog the organs until they no longer are able to function—sometimes at a very rapid pace. I have been treated for primary (AL) amyloidosis, a blood or bone marrow disorder.

In addition to AL amyloidosis, there are also thousands of cases of inherited (familial) and age-related amyloidosis. The most common familial type of amyloidosis was found to be caused by mutations in a protein made in the liver. This is the form of amyloidosis that may be present in a significant number of African-Americans.

Older Americans are susceptible to heart disease due to amyloidosis formed from the non-mutated form of the same protein. Another type of amyloidosis, secondary or reactive amyloidosis, occurs in patients with chronic infections or inflammatory diseases.

It was not until the 1980s that research identified the most common amyloid proteins and rationales for treatment began being discussed. The first clinical trial using oral chemotherapy for primary amyloidosis was begun 27 years ago, and high dose chemotherapy with stem cell transplantation was developed in 1994. The first liver transplant in the United States for familial amyloidosis was performed in 1992.

All of these types of amyloidosis, left undiagnosed or untreated, are fatal. 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.

AMYLOIDOSIS TREATMENT

The Amyloidosis Center at Boston University School of Medicine and Boston Medical Center, and other centers for amyloidosis treatment, have found that high dose intravenous chemotherapy followed by stem cell transplantation is an effective treatment in selected patients with primary amyloidosis. Abnormal bone marrow cells are killed through high dose chemotherapy, and the patient's own extracted blood stem cells are replaced in order to improve the recovery process.

The high dose chemotherapy and stem cell rescue and other new drugs have increased the remission rate and long-term survival dramatically. However, this treatment can also be life threatening and more research needs to be done to provide less risky forms of treatment.

RESEARCH

Although it has been 13 years since my initial stem cell transplant for amyloidosis, I, like most patients, am faced with recurring amyloidosis. Fortunately, due to research, there are new forms of treatment that are options for me and patients with recurring amyloidosis. These were not available 13 years ago. This is evidence that funding through Health and Human Services can make a difference.

The limited research and equipment funding through HHS and NIH has been helpful in developing new treatment alternatives for some patients with amyloidosis. Although funding is severely limited, researchers are moving forward to develop targeted treatments that will specifically attack the amyloid proteins.

The current funding for amyloidosis research shows what might be possible with increased funding and emphasis on the disease—but it does not go far enough.

Additional funding for research and equipment is needed to accomplish this task. Only through more research is there hope of further increasing the survival rate and finding additional treatments to help more patients.

DIAGNOSIS

Timely diagnosis is also of great concern. Although I was diagnosed at a very early stage of the disease, many people are diagnosed after the point that they are physically able to undertake treatment.

Early diagnosis and treatment are the keys to success. More needs to be done in these areas to alert health professionals to identify this disease.

CURRENT INITIATIVES

Through the leadership of this Committee and the further involvement of the U. S. Government, a number of positive developments have occurred.

- The National Institutes of Health has substantially increased its interest in amyloidosis. The NIH, particularly the Office of Rare Diseases, participates in meetings and symposia and works closely with organizations doing research and outreach on amyloidosis. The Amyloidosis Research Consortium (ARC), a network of clinical centers caring for amyloidosis patients, has developed and is working with the Food and Drug Administration and pharmaceutical companies to more rapidly test new therapies for amyloidosis.

- Research supported by the National Institute of Neurologic Disorders and Stroke at NIH and the Office of Orphan Products Development at the Food and Drug Administration led to successful repurposing of a generic drug that markedly slows progression of familial amyloidosis. This was the first drug treatment for this disease and worked by stabilizing the precursor protein. In partnership with pharmaceutical companies, new types of treatment, RNA interference, that work by decreasing production of the precursor protein are now in clinical trials. There is also hope, with increased funding for research, to expand the range of treatment to other categories of amyloidosis.

- There has been increased basic and clinical research at the Boston University Amyloidosis Center: models of light chain (AL) amyloid disease have been developed; serum chaperone proteins that cause amyloid precursor protein misfolding are being

identified; imaging techniques for the diagnosis of amyloid disease are being investigated, and new clinical trials for AL and familial amyloidosis are underway. A study of the age-related form of amyloid heart disease has provided natural history data indicating a shorter survival than had been previously appreciated for this under recognized form of amyloidosis. The National Institute of Aging has been supporting this work.

- Federal funding for research, equipment and treatment has been an important element in progress to date. Further funding is essential to speed the pace of discovery for basic and clinical research.

REQUEST FOR FISCAL YEAR 2017

Mr. Chairman, I ask that the Committee take the following actions to help address this deadly disease:

- First, include in the fiscal year 2017 Committee report language recommending that NIH expand its research efforts into amyloidosis, a group of rare diseases characterized by abnormally folded protein deposits in tissues.

- Second, direct the NIH to keep the Committee informed on the steps taken to increase the understanding of the causes of amyloidosis and the measures taken to improve the diagnosis and treatment of this devastating group of diseases.

Help me turn what has been my own life-threatening experience into hope for others.

Thank you for your consideration.

Testimony Regarding Fiscal Year 2017 Appropriations for Title VIII Nursing Workforce Development Programs
April 14, 2016

To: Subcommittee on Labor, Health & Human Services, Education, and Related Agencies, Committee on Appropriations, U.S. House of Representatives
Submitted by: Sharon Horner, PhD, RN, MC-CNS, FAAN
President, National Association of Clinical Nurse Specialists
Agency Addressed: Health Resources and Services Administration (HRSA)
Program: Title VIII Nursing Workforce Development Programs
Funding Request: $244 million in FY 2017

The National Association of Clinical Nurse Specialists (NACNS) is the voice of more than 72,000 clinical nurse specialists (CNSs). CNSs are licensed advanced practice registered nurses (APRN) who have graduate preparation (master's or doctorate) in nursing as a clinical nurse specialist. They have unique and advanced level competencies that meet the increased needs of improving quality and reducing costs in today's healthcare system. CNSs provide direct patient care, including assessment, diagnosis, and management of patient healthcare issues. They are leaders of change in health organizations, developers of scientific evidence-based programs to prevent avoidable complications, and coaches of those with chronic diseases to prevent hospital readmissions. CNSs are facilitators of multidisciplinary teams in acute and chronic care facilities to improve the quality and safety of care, including preventing hospital acquired infections, reducing length of stays, and preventing hospital readmissions.

The NACNS urges the subcommittee to fund *the **Title VIII Nursing Workforce Development Programs at $244 million in FY 2017.***

According to the Bureau of Labor Statistics (BLS), the registered nurse (RN) workforce will grow 16 percent from 2014 to 2024, outpacing the seven percent average for most other occupations. BLS also projects that this growth will result in 439,300 job openings, representing one of the largest numeric increases for all occupations.

In addition, employment of APRNs is projected to grow 31 percent from 2014 to 2024, much faster than the average for all occupations. Growth will occur because of an increase in the demand for healthcare services. Several factors will contribute to this demand, including a large number of newly insured patients resulting from healthcare legislation, an increased emphasis on preventive care, and the large, aging baby-boom population.

BLS notes that the healthcare sector is a critically important industrial complex for the nation. It is key to economic recovery with the number of jobs climbing steadily. Healthcare jobs are up nationwide, and BLS projects health-care occupations and industries to have the fastest employment growth and which will add the most jobs between 2014 and 2024. Over three million workers are in hospital settings, which often are the largest employer in a state. Healthcare has been a stimulus program generating employment and income, and nursing is the predominant occupation in the healthcare industry with more than 4.331 million active, licensed RNs in the United States in January 2016.

The Nursing Workforce Development Programs provide training for entry-level and advanced degree nurses to improve the access to, and quality of, healthcare in underserved areas. The Title VIII nursing education programs are fundamental to the infrastructure delivering quality, cost-effective healthcare. NACNS applauds the subcommittee's bipartisan efforts to recognize that a strong nursing workforce is essential to a health policy that provides high-value care for every dollar invested in capacity building for a 21st century nurse workforce.

The current federal funding falls short of the healthcare inequities facing our nation today. Absent consistent support, slight boosts to Title VIII will not fulfill the expectation of generating quality health outcomes, nor will episodic increases in funding fill the gap generated by a more than 15-year nurse and nurse faculty shortage felt throughout the U.S. health system.

NACNS believes that the deepening health inequities, inflated costs, and poor quality of healthcare outcomes in this country will not be reversed until the concurrent shortages of nurses, advanced practice registered nurses, and qualified nurse educators are addressed. Your support will help ensure that future nurses exist who are prepared and qualified to take care of you, your family, and all those who will need our care. Without national efforts of some magnitude to match the healthcare reality facing the nation today, it will be difficult to avoid the adverse effects on the health of our nation from the inability of our under resourced nursing education programs to produce sufficient numbers of high quality RNs and APRNs.

In closing, NACNS urges the subcommittee to maintain the ***Title VIII Nursing Workforce Development Programs by funding them at a level of $244 million in FY 2017***.

NACNS Contact Information:
Melinda Mercer Ray
Executive Director
National Association of Clinical Nurse Specialists
100 North 20th Street, 4th Floor
Philadelphia, PA 19103
Phone: 703-929-8995
Email: mray@nacns.org

Name: Brent A Morris

Title: Peer/Transitions Coordinator

Institutional Affiliation (if any) CIL, Living Independently for Today and Tomorrow

I am writing to support the National Council on Independent Living's request for Congress to reaffirm your commitment to the more than 57 million Americans disabilities by increasing funding in the HHS appropriations for Centers for Independent Living (CILs). I am asking that you increase funding by $200 million, for a total of $301 million for the Independent Living line item in FY 2017.

CILs are cross-disability, non-residential, community-based, nonprofit organizations that are designed and operated by individuals with disabilities. CILs are unique in that they are directly governed and staffed by people with all types of disabilities, including people with mental, physical, sensory, cognitive, and developmental disabilities. Each of the 365 federally funded centers provides five core services: information and referral, individual and systems advocacy, peer support, independent living skills training, and transition services, which were added with the passage of the Workforce Innovation and Opportunity Act (WIOA). From 2012-2014, CILs provided the core services to nearly 5 million people with disabilities, and provided additional services such as housing assistance, transportation, personal care attendants, and employment services to hundreds of thousands of individuals. During this same period, prior to transition being added as a core service, CILs transitioned 13,030 people with disabilities from nursing homes and other institutions into the community.

Transition services were added as a fifth core service with the 2014 reauthorization of the Rehabilitation Act within the Workforce Innovation and Opportunity Act. Transition services include the transition of individuals with significant disabilities from nursing homes and other institutions to home and community-based residences with appropriate supports and services, assistance to individuals with significant disabilities at risk of entering institutions to remain in the community, and the transition of youth with significant disabilities to postsecondary life. This core service is vital to achieving full participation for people with disabilities.

Every day, CILs are fighting to ensure that people with disabilities gain and maintain control over our own lives. We know that this cannot occur when people reside in institutional settings. Opponents of deinstitutionalization say that allowing people with disabilities to live in the community will result in harm. We know that the 13,030 people with disabilities who CILs successfully transitioned out of nursing homes and institutions from 2012-2014 prove otherwise. Additionally, when services are delivered in an individual's home, the result is a tremendous cost savings to Medicaid, Medicare, and states. Community-based services enable people with disabilities to become less reliant on long-term government supports, and they are significantly less expensive than nursing home placements. We are grateful that Congress demonstrated their understanding and support for community-based services when WIOA was passed and transition was added as a fifth core service.

Since transition services were added as a core service, the need for funding is critical. Moreover, CILs need additional funding to restore the devastating cuts to the Independent Living program, make up for inflation costs, and address the increased demand for independent living services. In

2016, the Independent Living Program is receiving $2.5 million less in funding than it was in 2010. It is simply not possible to meet the increasing demand for services and effectively provide transition services without additional funding. Increased funding should be reinvested from the billions currently spent to keep people with disabilities in costly Medicaid nursing homes and institutions and out of mainstream society.

Centers for Independent Living play a crucial role in the lives of people with disabilities, and work tirelessly to ensure that people with disabilities have a real choice in where and how they live, work, and participate in the community. Additionally, CILs are an excellent service and a bargain for America, keeping people engaged with their communities and saving taxpayer money. NCIL is dedicated to increasing the availability of the invaluable and extremely cost-effective services CILs provide, and they have submitted written testimony with a similar request. I strongly support NCIL's testimony.

Public Witness Testimony of Jill Kagan, Chair, National Respite Coalition for the House Subcommittee on Labor, HHS and Education Appropriations in support of funding for the Lifespan Respite Care Program Administration for Community Living (ACL), Dept. of Health and Human Services April 14, 2016

Mr. Chairman, I am Jill Kagan, Chair of the National Respite Coalition (NRC) is a network of state respite coalitions, respite providers, family caregivers, and national, state and local organizations that support respite. The NRC is **requesting that the Subcommittee include $5.0 million for the Lifespan Respite Care Program administered by the Administration for Community Living, Department of Health and Human Services, in the FY 2017 Labor, HHS, and Education and Related Agencies Appropriations bill as recommended in the President's FY 2017 budget.** This will enable:

- State replication of best practices in Lifespan Respite to allow family caregivers, regardless of the care recipient's age or disability, to have access to affordable respite, and to be able to continue to play the significant role in long-term care that they are fulfilling today, saving Medicaid billions;
- Improvement in the quality of respite services currently available;
- Expansion of respite capacity to serve more families by building new and enhancing current respite options, including recruitment and training of respite workers and volunteers; and
- Greater consumer direction by providing family caregivers with training and information on how to find, use and pay for respite services.

Who Needs Respite? More than 43 million adults in the U.S. are family caregivers of an adult or a child with a disability or chronic condition (*National Alliance for Caregiving (NAC) and AARP Public Policy Institute, 2015).* The estimated economic value of family caregiving of adults alone is approximately $470 billion annually (*AARP Public Policy Institute, 2015*). Eighty percent of those needing long-term services and supports (LTSS) are living at home. Two out of three (66%) older people with disabilities who receive LTSS at home get all their care exclusively from family caregivers (*Congressional Budget Office, 2013*). This percentage will only rise in the coming decades with greater life expectancies of individuals with disabling and chronic conditions living at home with their aging parents or other caregivers, the aging of the baby boom generation, and the decline in the percentage of the frail elderly who are entering nursing homes.

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%) (*NAC and AARP, 2015*). The most recent

National Survey of Children with Special Health Care Needs found that 11 million children under age 18 have special health care needs[1] (*Health Resources and Services Administration, 2013*).

National, State and local surveys have shown respite to be the most frequently requested service by family caregivers *(The Arc, 2011; National Family Caregivers Association, 2011*). **Yet, 85% of family caregivers of adults are not receiving respite services at all** *(NAC and AARP, 2015).* Nearly half of family caregivers of adults (44%) identified in the *National Study of Caregiving* were providing substantial help with health care tasks. Of this group, despite their high level of care, fewer than 17% used respite (*Wolff, J., et al., 2016*).

Families of the wounded warriors, military personnel who returned from Iraq and Afghanistan with traumatic brain injuries and other serious chronic and debilitating conditions, don't have full access to respite. Even with enactment of the VA Family Caregiver Support Program which serves only veterans since 9/11, the need for respite remains high for all veterans and their family caregivers. A 2014 Rand Corporation report prepared for the Elizabeth Dole Foundation, Hidden Heroes: America's Military Caregivers, recommended that respite care should be more widely available to military caregivers *(Ramchand, et al., 2014).* The Dole Foundation's Respite Impact Council found that traditional respite services do not address the needs of military caregivers and the Lifespan Respite Care program should be fully funded to help meet those needs.

Respite Barriers and the Effect on Family Caregivers. While most families want to care for family members at home, research shows that family caregivers are at risk for serious emotional stress and mental and physical health problems *(NAC and AARP; 2015; American Psychological Association, 2012; Spillman, BC, 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 abuse from caregivers among care recipients with significant needs increases when caregivers themselves are depressed or in poor health *(American Psychological Association, nd).* Parents of children with special health care needs report poorer general health, more physical health problems, worse sleep, and increased depressive symptoms compared to parents of typically developing children (*McBean, A, et al, 2013).*

Respite, that has been shown to ease family caregiver stress, is too often out of reach or completely unavailable. Restrictive eligibility criteria preclude many families from receiving services. Many children with disabilities age out of the system when they turn 21 and lose services, such as respite. A survey of nearly 5000 caregivers of individuals with intellectual and developmental disabilities (I/DD) found the vast majority of caregivers report physical fatigue (88%), emotional stress (81%) and emotional upset or guilt (81%); 1 out of 5 families (20%)

[1] The U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau (MCHB) defines children with special health care needs (CSHCN) as "...those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally."

report that someone in the family quit their job to provide care; and more than 75% of family caregivers could not find respite services *(The Arc, 2011)*. Despite their higher burden of care, caregivers of persons with dementia are more prone to underutilizing and/or delaying respite. The *2013 Johns Hopkins Maximizing Independence at Home Study*, in which researchers surveyed persons with dementia residing at home with their informal caregivers, found that nearly half of the caregivers had unmet needs for mental health care and most of these, according to the researchers, needed emotional support or respite care *(Black, B., et al., 2013)*. Respite may not exist at all for individuals with conditions such as ALS, MS, spinal cord or traumatic brain injuries, or children with serious emotional conditions or autism.

Barriers to accessing respite include fragmented and narrowly targeted services, cost, and the lack of information about respite or how to find or choose a provider. A critically short supply of well-trained respite providers may prohibit a family from making use of a service they so desperately need. Lifespan Respite is designed to help states eliminate barriers through improved coordination and capacity building.

Respite Benefits Families and is Cost Saving. Respite has been shown to help reduce the stress that can lead poor health among family caregivers. In turn, respite helps avoid or delay out-of-home placements, minimizes precursors that can lead to abuse and neglect, and strengthens marriages and family stability. While limitations in respite research exist, these findings were recently corroborated by a review of the literature conducted by an Expert Panel on Respite Research, convened by ARCH with support from ACL (*Kirk, R., 2015*). For example, a study of parents of children with autism found that respite was associated with reduced stress and improved marital quality *(Harper, D., et al., 2013)*. A US Department of Health and Human Services report found that reducing key stresses on caregivers through services such as respite would reduce nursing home entry *(Spillman and Long, USDHHS, 2007)*. In a survey of caregivers of individuals with Multiple Sclerosis, two-thirds said that respite would help keep their loved one at home. When the care recipient with MS also has cognitive impairment, the percentage of those saying respite would be helpful to avoid or delay nursing home placement jumps to 75% *(NAC, 2012)*.

Compelling budgetary benefits accrue because of respite. Delaying a nursing home placement for one person with Alzheimer's or avoiding hospitalization for a child with autism can save Medicaid and other government programs thousands 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% drop in the odds of hospitalization *(Mandell, D., et al., 2012)*. In the private sector, 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, D., 2011)*. Respite for working family caregivers could improve job performance, saving employers billions.

Lifespan Respite Care Program Helps. The federal Lifespan Respite program, administered by the Administration for Community Living (ACL) provides competitive grants to eligible state agencies. Congress appropriated $2.5 million each year from FY09 - FY12 and slightly less in FY13-FY15. Since 2009, 33 states and DC have received Lifespan Respite Grants. In FY 2016, the program received $3.3 million. While current or past grantees will receive no new funding this year, an additional 2-3 new states are expected to be funded. States are required to establish state and local coordinated Lifespan Respite care systems to serve families regardless of age or special need, provide new planned and emergency respite services, train and recruit respite workers and volunteers and assist caregivers in gaining respite access. Lifespan Respite helps states maximize use of limited resources across age and disability groups and deliver services more efficiently. Increasing funding, even slightly, for the program in FY 17 could allow funding of several new states and help current grantees complete their ground-breaking work.

How is Lifespan Respite Program Making a Difference? With limited funds, Lifespan Respite grantees are engaged in innovative activities such as:

- **Alabama, Arizona, Delaware, Montana, Nebraska, Nevada, North Carolina, Oklahoma, Rhode Island, South Carolina, Tennessee, Virginia**, and **Washington** have successfully used consumer-directed respite vouchers for serving underserved populations, such as individuals with MS or ALS, adults with intellectual or developmental disabilities (I/DD), or those on waiting lists for services.
- **Idaho, Illinois, Iowa,** and **Nebraska** offer emergency respite support.
- **Alabama, Arizona, Colorado, Massachusetts, Nebraska, New York, Ohio, Pennsylvania, South Carolina** and **Tennessee** are providing new volunteer or faith-based respite.
- Innovative and sustainable respite services, funded in **Colorado, Massachusetts, North Carolina** and **Ohio** through mini-grants to community-based agencies, have documented benefits to family caregivers.
- Respite provider recruitment and training are priorities in **New Hampshire, Virginia,** and **Wisconsin**.

Additional partnerships between state agencies are changing the landscape. The AZ Lifespan Respite program housed in Aging and Adult Services partnered with AZ's Children with Special Health Care Needs Program to provide respite vouchers to families across the age and disability spectrum. The OK Lifespan Respite program partnered with the state's Transit Administration to develop mobile respite to serve isolated rural areas of the state. States are building respite registries and "no wrong door systems" in partnership with Aging and Disability Resource Centers to help family caregivers access respite and funding sources. Funding must be maintained to help sustain these innovative state efforts. States are developing long-term sustainability plans, but without federal support, many of the grantees will be cut off before these initiatives achieve their full impact.

No other federal program mandates respite as its sole focus, helps ensure respite quality or choice, and allows funds for respite start-up, training or coordination to address accessibility and affordability issues for families. With tens of millions of families affected, **caregiving is a public health issue requiring an immediate proven preventive response**, such as respite. We urge you to include $5 million in the FY 2017 Labor, HHS, and Education appropriations bill. This will allow Lifespan Respite Programs to be replicated and sustained. Families, with access to respite, will be able to keep their loved ones at home, saving Medicaid and other federal programs, billions of dollars.

Complete references available upon request. Please contact the NRC for more information. *http://archrespite.org/national-respite-coalition*

Statement by the Association of American Medical Colleges on FY 2017 Appropriations for the Department of Health and Human Services Submitted for the Record to the House Appropriations Subcommittee on Labor, Health and Human Services, Education and Related Agencies – April 15, 2016

The Association of American Medical Colleges is a not-for-profit association dedicated to transforming health care through innovative medical education, cutting-edge patient care, and groundbreaking medical research. Its members comprise all 145 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 148,000 faculty members, 83,000 medical students, and 115,000 resident physicians.

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 $34.5 billion for the National Institutes of Health (NIH); $364 million in budget authority for the Agency for Healthcare Research and Quality (AHRQ); $524 million for the Title VII health professions and Title VIII nursing workforce development programs at the Health Resources and Services Administration (HRSA)'s Bureau of Health Workforce; and continued support for student aid through the Department of Education and HRSA's National Health Service Corps. The AAMC appreciates the Subcommittee's longstanding, bipartisan efforts to strengthen these programs.

National Institutes of Health – Congress's long-standing bipartisan support for medical research through the NIH has created a scientific enterprise that is the envy of the world and 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.

Nearly 84 percent of the NIH's budget is competitively awarded through almost 50,000 research and training grants to more than 300,000 researchers at over 2,500 universities and research institutions located in every state. At least half of this funding supports life-saving research at America's medical schools and teaching hospitals, where scientists, clinicians, fellows, residents, medical students, and trainees work side-by-side to improve the lives of Americans through research.

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 foster discovery, improve our understanding of the underlying cause of disease, and translate this knowledge into the next generation of diagnostics, therapeutics, and other clinical innovations. This partnership not only lays the foundation for improved health and quality of life, but also strengthens the nation's long-term economy.

The AAMC thanks Congress for the bipartisan support that resulted in the inclusion of $32.1 billion in the FY 2016 omnibus spending bill for medical research conducted and supported by the NIH.

If this nation is to continue to meet current and emerging health challenges, improve our nation's health, sustain our leadership in medical research, and remain competitive, it is essential to sustain predictable increases in the NIH budget.

The AAMC supports the Ad Hoc Group for Medical Research recommendation that Congress appropriates at least $34.5 billion through the Labor-HHS-Education spending bill for FY 2017. This $2.4 billion increase represents 5 percent real growth above the projected rate of biomedical inflation, and will help ensure that NIH-funded research can continue to improve our nation's health and enhance our competitiveness in today's global information and innovation-based economy.

The AAMC continues to be concerned about the long-lasting impact of the decline in the NIH budget on the next generation of scientists, who see training funds threatened and the possibility of sustaining a career in research diminished. The continued success of the biomedical research enterprise relies heavily on the imagination and dedication of a diverse and talented scientific workforce. Of particular concern is the challenge of maintaining a cadre of clinician-scientists to facilitate translation of basic research to human medicine. NIH supports many innovative training programs and funding mechanisms that foster scientific creativity and exploration.

Additional funding is needed if we are to strengthen our nation's research capacity, ensure a biomedical research workforce that reflects the racial and gender diversity of our citizenry, and inspire a passion for science in current and future generations of researchers.

The AAMC is disappointed the Subcommittee last year once again proposed to reduce the limit on salaries that can be drawn from NIH extramural awards at Executive Level III of the Federal Executive Pay Scale. Medical schools' and teaching hospitals' discretionary funds from clinical revenues and other sources have become increasingly constrained and less available to invest in research. If institutions and departments divert funds to compensate for a reduction in the salary limit, they have less funding for critical activities such as bridge funding to investigators between grants and start-up packages to young investigators to launch their research programs. A lower salary cap also will disproportionately affect physician investigators, who will be forced to make up salaries from clinical revenues, thus leaving less time for research. This may serve as a deterrent to their recruitment into research careers. The AAMC urges the Subcommittee to retain the limit at Executive Level II.

Agency for Healthcare Research and Quality – Complementing the medical research supported by NIH, AHRQ sponsors health services research designed to improve the quality of health care, decrease health care costs, and provide access to essential health care services by translating research into measurable improvements in the health care system. The AAMC firmly believes in the value of health services research as the nation continues to strive to provide high-quality, evidence-based, efficient, and cost-effective health care to all of its citizens. The AAMC

joins the Friends of AHRQ in recommending $364 million in budget authority for the agency in FY 2017.

The AAMC is disappointed the Subcommittee last year proposed to eliminate AHRQ. As the only federal agency with the sole purpose of generating evidence to make health care safer; higher quality; and more accessible, equitable, and affordable, AHRQ works to ensure such evidence is available across the continuum of health care stakeholders, from patients to payers to providers. These research findings will better guide and enhance consumer and clinical decision-making, provide improved health care services, and promote efficiency in the organization of public and private systems of health care delivery.

Health Professions Funding – HRSA's Title VII health professions and Title VIII nursing workforce development programs are the only federal programs designed to improve the supply, distribution, and diversity of the nation's primary care workforce. Through loans, loan guarantees, and scholarships to students, and grants and contracts to academic institutions and non-profit organizations, the Title VII and Title VIII programs fill the gaps in the supply of health professionals not met by traditional market forces.

Titles VII and VIII are structured to allow grantees to test educational innovations, respond to changing delivery systems and models of care, and address timely topics in their communities. By assessing the needs of the communities they serve and emphasizing interprofessional education and training, Title VII and VIII programs bring together knowledge and skills across disciplines to provide effective, efficient and coordinated care. Further, studies demonstrate that the programs graduate more minority and disadvantaged students and prepare providers that are more likely to serve in Community Health Centers (CHC) and the National Health Service Corps (NHSC).

In addition to promoting educational innovations and preparing the workforce for changing delivery systems, the programs also support faculty development, curriculum development, and continuing education opportunities. These are all important components to ensure faculty and providers are equipped to meet the nation's changing needs and train the next generation of health professionals.

The AAMC joins the Health Professions and Nursing Education Coalition (HPNEC) in recommending $524 million for these important workforce programs in FY 2017. This funding level is necessary to ensure continuation of all existing Title VII and Title VIII programs while also supporting promising initiatives such as the Pediatric Subspecialty Loan Repayment program, the Clinical Training in Interprofessional Practice program, the Rural Physician Training Grants, and other efforts to bolster the workforce. Additionally, because HRSA has been administering the Behavioral Health Workforce Education and Training Program, we also support the President's FY 2017 budget proposal of shifting funds previously appropriated to the Substance Abuse and Mental Health Services Administration to HRSA.

The AAMC objects to the Administration's proposal to eliminate the Title VII Area Health Education Centers (AHEC) program, which, in academic year 2014-2015 alone, trained health professions students in over 11,000 sites across the country, including community-based and

ambulatory care settings and CHCs. We appreciate the Administration's proposal to enhance the focus on academic support and pre-professional engagement for students from disadvantaged backgrounds through supporting the Health Careers Opportunity Program (HCOP). Research shows that HCOP has helped students from disadvantaged backgrounds throughout the educational pipeline achieve higher grade point averages and matriculate into health professions programs. Continued support for these and the full spectrum of Title VII programs is essential to prepare our next generation of medical professionals to adapt to the changing health care needs of the nation's aging and increasingly diverse population.

In addition to funding for Title VII and Title VIII, HRSA's Bureau of Health Workface also supports the Children's Hospitals Graduate Medical Education (CHGME) program. This program provides critical federal graduate medical education support for children's hospitals to prepare the future primary care and specialty care workforce for our nation's children. We strongly support full funding for the Children's Hospitals Graduate Medical Education program at $300 million in FY 2017.

Student Aid and the National Health Service Corps (NHSC) – The AAMC urges the Subcommittee to sustain student loan and repayment programs for graduate and professional students at the Department of Education. The average graduating debt of medical students is currently $183,000, and typical repayment can range from $329,000 to $480,000.

Along with more than 50 stakeholder organizations, the AAMC urges the Subcommittee to provide a discretionary appropriation for the National Health Service Corps (NHSC) in FY 2017. As the nation faces multiple health professional shortages, sustained investments in workforce programs are necessary to help care for our nation's most vulnerable populations.

Recognizing that mandatory funding may be provided through other mechanisms, the appropriations committees retain primary responsibility for funding the administrative functions of the NHSC and for avoiding budgetary lapses in future years. We look forward to working with Congress to help ensure a long-term investment in the NHSC without sacrificing other federal health professions training support.

Once again, the AAMC appreciates the opportunity to submit this statement for the record and looks forward to working with the Subcommittee as it prepares its FY 2017 spending bill.

Testimony Prepared by Karen Pearl, President & CEO of God's Love We Deliver for the United State House Subcommittee on Labor, Health and Human Services, Education, and Related Agencies addressed to the Department of Health and Human Services

April 15, 2015

God's Love We Deliver is part of a nationwide coalition, the Food is Medicine Coalition, of food and nutrition services providers, affiliates and their supporters across the country that provide food and nutrition services to people living with HIV/AIDS (PWH) and other chronic illnesses. In our service area, we provide 1.5 million medically tailored, home delivered meals annually. Collectively, the Food is Medicine Coalition is committed to increasing awareness of the essential role that food and nutrition services (FNS) play in successfully treating HIV/AIDS and to expanding access to this indispensable intervention for people living with other severe illnesses.

1.) Why Food and Nutrition Services (FNS) Matter for PWH

While adequate food and nutrition are basic to maintaining health for all persons, good nutrition is crucial for the management of HIV infection. Proper nutrition is needed to increase absorption of medication, reduce side effects, and maintain healthy body weight. Research has identified the virus as an independent risk factor for cardiovascular, liver and kidney disease, cancer, osteoporosis and stroke. Several HIV medications can cause nausea and vomiting and some can affect lab results that test lipids and kidney and liver function. These compounding health effects, caused by the virus and its medications, reinforce the important role a nutrient-rich diet plays in a patient's overall care plan. In addition, providing food and nutrition services can serve to facilitate access and engagement with medical care, especially among vulnerable populations.

The Food and Nutrition Services category within the Ryan White Program includes medical nutritional therapy (MNT) and food and nutrition services (FNS). MNT covers nutritional diagnostic, therapy, and counseling services focused on prevention, delay or management of diseases and conditions, and involves an in-depth assessment, periodic reassessment and intervention provided by a licensed, Registered Dietitian Nutritionist (RDN) outside of a primary care visit. The range of FNS provided through the Ryan White program complements the needs of PWH at any stage of their illness. For those who are most mobile, there are congregate meals, walk-in food pantries and voucher programs. For those whose disease has progressed, home-delivered meals and home-delivered grocery bags complement their medical treatment.

Since 2006, HRSA has included MNT and FNS, provided under the guidance of RDNs, as a clinically effective **core medical service** in the Ryan White Program. These services play a critical role in ensuring that PWH enter and continue in primary medical care, adhere to their medications, and ultimately achieve viral suppression.

2.) FNS as a Care Completion Service Unique to Ryan White

Social and economic interventions, most often in the form of care completion service like food and nutrition services, are fundamental to making health care work for PWH. Support services for PWH are not covered in any comprehensive way by Medicaid or other public insurance initiatives that have been expanded by the Affordable Care Act. As the HIV epidemic in the United States increasingly impacts low-income individuals, support services help stabilize individuals living with or at risk of HIV. When needs are met, and life's emergencies are held at bay, PWH are poised to remain connected to care and treatment.

3.) Access to FNS and the Triple Aim

Access to appropriate food and nutrition services (FNS) are increasingly recognized as key to accomplishing the triple aim of national healthcare reform for PWH.

Better Health Outcomes

When clients get effective FNS and become food secure, they then keep scheduled primary care visits, score higher on health functioning, are at lower risk for inpatient hospital stays and are more likely to take their medicines[i]. Studies show both the health benefits of access to MNT and/or nutrition counseling for people with HIV infections[ii] and the resulting decreases in their healthcare costs. Compare these outcomes to PWH who are food insecure, who have:

- Lower CD4 counts & lower likelihoods of having undetectable viral loads[iii]
- More ER visits[iv] & increased morbidity and mortality[v]
- More missed primary care appointments & reduced use of antiretroviral therapy[vi].

Lower Healthcare Costs

Millions of dollars in healthcare expenditures are saved through the provision of FNS to PWH. A recent study comparing participants in a medically-tailored FNS program vs. a control group within a local managed care organization found that average monthly healthcare costs for PWH fell 80% in first three months after receiving FNS[vii]. If hospitalized, nourished clients' costs were 30% lower, their hospital length of stay was cut by 37% and they were 20% more likely to be able to be discharged to their homes rather than a more expensive institution[viii]. Furthermore, FNS are a very inexpensive intervention. For each day in a hospital saved, you can feed a person a medically-tailored diet for half a year.

Improved Patient Satisfaction

Studies show nutrition counseling improves quality of life[ix]. Members overwhelmingly report that our services help them live more independently, eat more nutritiously and manage their medical treatment more effectively.

4.) FNS and the National HIV/AIDS Strategy (NHAS)

Access to FNS for PWH is fundamental to fulfilling the goals of the NHAS.

- **NHAS Goal: Reducing new HIV infections:** PWH who are food insecure are less likely to have undetectable viral loads in a statistically significant way. Undetectable viral loads prevent transmission 96% of the time[x], thus, FNS is key to prevention[xi].
- **NHAS Goal: Increasing access to care and improving health outcomes for people living with HIV:** PWH who receive effective FNS are more likely to keep scheduled primary care

visits, score higher on health functioning, are at lower risk for inpatient hospital stays and are more likely to take their medicines[xii].

- **NHAS Goal: Reducing HIV-related disparities and health inequities:** By providing FNS to PWH who are in need largely because of poverty, we improve health outcomes, thereby reducing health disparities[xiii].
- **NHAS Goal: Achieving a more coordinated national response to the HIV epidemic:** There remains a tremendous variation by state in coverage of food and nutrition services both inside and outside of Ryan White, making support for Ryan White HIV Program all the more needed. Ultimately, if we are going to achieve a more coordinated national response to the HIV epidemic and our quest to reduce healthcare spending nationwide, FNS must be included in all healthcare reform efforts, including Ryan White and the ACA.

Conclusion

We are deeply aware of the difficult decisions that face the members of the Committee in the current fiscal environment. Yet, research shows that investment in FNS, with the great return in prevention and retention in HIV care, are vital to lowering the number of new infections in the domestic HIV epidemic and ultimately reducing healthcare costs and preserving healthcare resources for the future. A client's diet can literally have life and death consequences. When people are severely ill, good nutrition is one of the first things to deteriorate, making recovery and stabilization that much harder, if not impossible. Early and reliable access to medically-appropriate FNS helps PWH live healthy and productive lives, produces better overall health outcomes and reduces health care costs.

Along with our colleagues, we appreciate the opportunity to offer this testimony regarding the FY 2017 Appropriations process. We are also pleased to offer our assistance and expertise, including information from our Research Library.

Thank you.

Karen Pearl
President & CEO
God's Love We Deliver
166 Avenue of the Americas
New York, NY 10013
212-294-8171
kpearl@glwd.org

---

[i] Aidala A, Yomogida M, Vardy Y & the Food & Nutrition Study Team. Food and Nutrition Services, HIV Medical Care, and Health Outcomes. New York State Department of Health: Resources for Ending the Epidemic, 2014. Available at https://www.health.ny.gov/diseases/aids/ending_the_epidemic/docs/key_resources/housing_and_supportive_services/chain_factsheet3.pdf

[ii] Academy of Nutrition and Dietetics (formerly American Dietetic Association). HIV/AIDS Nutrition Evidence Analysis Project at http://www.adaevidencelibrary.com/conclusion.cfm?conclusion_statement_id=250707 Accessed 29 July 2012.

[iii] Aidala A., Yomogida M., and the HIV Food & Nutrition Study Team (2011);

Singe AW,Weiser SD, McCoy, SI. Does Food Insecurity Undermine Adherence to Antiretroviral Therapy? A Systematic Review. AIDS Behav (2015) 19:1510–1526.

[iv] Ibid.

[v] Anema A, Chan K, Yip B, Weiser S, Montaner JSG, Hogg RS. Impact of food insecurity on survival among HIV-positive injection drug users receiving antiretroviral therapy in a Canadian cohort. 141st APHA Annual Meeting, Nov. 2-6, 2013. Boston, MA. Abstract #: 290277

[vi] Aidala A., Yomogida M., and the HIV Food & Nutrition Study Team (2011).

[vii] Gurvey J, Rand K, Daugherty S, Dinger C, Schmeling J, Laverty N. Examining Health Care Costs Among MANNA Clients and a Comparison Group. J Prim Care Community Health. (2013) 4:311-317

[viii] Ibid.

[ix] Rabeneck L, Palmer A, Knowles JB, Seidehamel RJ, Harris CL, Merkel KL, Risser JMH, Akrabawi SS. A randomized controlled trial evaluating nutrition counseling with or without oral supplementation in malnourished HIV-infected patients. J Am Diet Assoc. (1998) 98: 434-438;Schwenk A, Steuck H, Kremer G. Oral supplements as adjunctive treatment to nutritional counseling in malnourished HIV-infected patients: randomized controlled trial. Clinical Nutrition (1999) 18(6): 371-374.

[x] M. S. Cohen *et al.*, Prevention of HIV-1 Infection with Early Antiretroviral Therapy. N. Engl. J. Med.(2011) 365, 493-505 . HPTN 052

[xi] Palar K, Laraia B, Tsai A, Weiser SD Food insecurity is associated with sexually transmitted infections and HIV serostatus among low income adults in the National Health and Nutrition Examination Survey (NHANES) (1999-2010). Presented at the American Public Health Association 141st Annual Meeting, Boston, MA, November 5, 2013.

[xii] Aidala A, Yomogida M, Vardy Y & the Food & Nutrition Study Team. Food and Nutrition Services, HIV Medical Care, and Health Outcomes. New York State Department of Health: Resources for Ending the Epidemic, 2014. Available at

xiii Weiser SD, Frongillo EA, Ragland K, Hogg RS, Riley ED, Bangsberg DR. Food insecurity is associated with incomplete HIV RNA suppression among homeless and marginally housed HIV-infected individuals in San Francisco. J Gen Intern Med. (2009) 24(1):14-20.

Adult Congenital Heart Association
Labor-Health and Human Services-Education Appropriations Subcommittee
National Institutes of Health and the Centers for Disease Control and Prevention National Center on Birth Defects and Developmental Disabilities

My name is Glenn Tringali, National Executive Director of the Adult Congenital Heart Association (ACHA). On behalf of ACHA, I am pleased to submit testimony in support of funding for the National Institutes of Health (NIH) and the Centers for Disease Control and Prevention's (CDC) National Center on Birth Defects and Developmental Disabilities (NCBDDD). We urge you to include $34.5 billion for NIH and $10 million for congenital heart disease at NCBDDD in the Labor-Health and Human Services-Education appropriations bill for FY2017.

Founded in 1998 by a group of adult congenital heart defect survivors and their families, the ACHA and its Board of Directors continues to consist primarily of those living with heart defects. ACHA is dedicated to promoting excellence in adult congenital heart disease (ACHD). Our mission is to improve and extend the lives of the millions born with heart defects through education, advocacy and the promotion of research.

The success of childhood cardiac intervention has created a new and growing patient population of those living with CHDs into adulthood. Thanks to the increase in survival, of the over 2 million people alive today with CHD, more than half are adults, increasing at an estimated rate of 5 percent each year. Few congenital heart survivors are aware of their high risk of additional problems as they age, facing high rates of neuro-cognitive deficits, heart failure, rhythm disorders, stroke, and sudden cardiac death. Many survivors require multiple operations throughout their lifetime. Fifty percent of all congenital heart survivors have complex problems for which lifelong care from an adult congenital heart specialist, who has training is more specialized than a general cardiologist, is required. Yet less than 10 percent of adult congenital heart patients receive this cardiac care. Delays in care can result in premature death and disability. In adults, this often occurs during prime wage-earning years.

National Institutes of Health
The National Heart Lung and Blood Institute (NHLBI) is the research home for congenital heart disease. The research undertaken there is one of the primary reasons children born with CHDs are living into adulthood. We believe that the one critical challenge for adults with CHD is the matter of continued expert care across the lifespan. Continued research into better quality of care for those with CHDs – whether it be better surgical techniques or a better understanding of what those with CHDs face as they age – is a critical area for NHLBI to address.

To advance research on CHDs, NHLBI should prioritize the following research areas:

- **Advancing Translational Research**: Ensuring that basic science is translated into clinical practice is essential. While there have been great strides in ensuring that babies born with CHD are identified and repaired, we know that there are lifelong implications for those with CHDs that require continued follow-up and treatment. As the proportion of

adults with CHD grows larger than the pediatric population, NHLBI must look at this area as an opportunity for advancing translational research. It is an area of great need.

- **Development of Workforce and Resources**: No where do we see a greater need than in the area of workforce, specifically for experts in CHD. We are working with others to ensure that those with CHDs have access to the best care, but the continued need for additional partners remains. Ensuring that researchers and clinicians have the training and resources available to address areas of need is essential. Focusing on ensuring access to science and care will certainly further the needs of this important population as well as the broader heart health community.

National Center on Birth Defects and Developmental Disabilities

Despite its prevalence and significance, there are gaps in research and standards of care for CHD patients. Previous Congressional support for the congenital heart disease activities at the NCBDDD has yielded an increased understanding of the public health burden of this condition, but additional resources are required to continue and expand these efforts. Continued federal investment is necessary to provide rigorous epidemiological and longitudinal public health surveillance and research on infants, children, adolescents, and adults to better understand congenital heart disease across the lifespan, improve outcomes, and reduce costs.

Increasing congenital heart disease funding at the CDC to $10.0 million in FY 2017 would allow for improved awareness of CHDs and understanding of prevalence, healthcare utilization, and short and long-term physical and psychosocial outcomes, achieved by building upon the pilot congenital heart adolescent and adult surveillance program, incorporating public health research, developing a longitudinal cohort, and completing a survivorship study. This funding would allow NCBDDD to develop a report on adult congenital heart disease surveillance efforts, including an estimated number of individuals in the US living with a CHD, epidemiology of CHDs across the life span, age-specific prevalence and factors associated with those patients "lost to care" who may have dropped out of appropriate specialty care. Having this information is critical to meeting the needs of adults with CHDs.

To: House Appropriations Committee
Outside Witness Testimony from: William Smith, Executive Director, National Coalition of STD Directors

CDC's Division of STD Prevention Funding History	
FY2017 Funding Request:	**$165.4 million***
FY2017 PB Request:	$157.3 million
FY2016 Funding Level:	$157.3 million
FY2015 Funding Level:	$157.3 million
FY2014 Funding Level:	$157.7 million
FY2013 Funding Level:	$154.9 million
FY2012 Funding Level:	$163 million
**A requested increase of $8.1 million*	

On behalf of the members of the National Coalition of STD Directors (NCSD), I am writing to request an additional $8.1 million for the Division of STD Prevention in fiscal year (FY) 2017 funding. The Division of STD Prevention is part of the National Center for HIV/AIDS, Viral Hepatitis, STD and TB Prevention at the Centers for Disease Control and Prevention (CDC). NCSD members represent sexually transmitted disease (STD) programs in all fifty states, seven cities counties and eight U.S. territories.

STDs remain major epidemics in the United States. Each year, there are nearly 20 million new cases of STDs, approximately half of which go undiagnosed and untreated. These new STDs cost the U.S. health care system $16 billion every year—and cost individuals even more in immediate and life-long health consequences, including infertility and a higher risk of certain cancers. In addition, having other STDs increases the likelihood of contracting HIV, and in turn, having HIV also increases the likelihood of contracting and spreading STDs. Investments in STD prevention and treatment further the National HIV/AIDS Strategy's goal of reducing new HIV infections.

CDC's Division of STD Prevention (DSTDP) guides national efforts to prevent and control STDs. DSTDP invests most of its federal funding in state, territorial, and large city or county health departments who carry out on-the-ground efforts to control STDs. State, territorial, and local public health STD programs are the backbone of our national STD infrastructure, not only monitoring and controlling STD epidemics, but responding to emergency outbreaks of all kinds, from Ebola to food-borne illnesses to flu. However, the current public health infrastructure has been continually strained by budget reductions at the federal, state, and local levels and is currently not sufficiently prepared for the reality of rising rates of STDs, particularly syphilis, and other outbreaks.

Today, STD programs in these departments across the country are facing skyrocketing syphilis rates, including increases in congenital syphilis. In fact, last year, for the first time since 2006, rates for chlamydia, gonorrhea, and syphilis all increased concurrently. DSTDP and these health departments across the country need additional federal resources to reverse the alarming and costly trends of STDs. Flat funding will not address these growing needs for outreach, treatment assurance and surveillance. In fiscal year 2017 funding, please support an urgent funding increase of $8.1 million to the CDC's Division of STD Prevention to ensure those on the front lines of STD prevention have funding to respond to the rising STD rates, particularly syphilis, and prepare for other unforeseen outbreaks.

Increasing Syphilis Rates, Including Congenital Syphilis

Additional funding is needed to address our syphilis epidemic and to ensure the needs of hard to reach populations are addressed. In 2014, for the third year in a row, reported cases of primary and secondary syphilis – the stages where the infection is most likely to spread – have

increased by double digits. In 2012, primary and secondary syphilis increased by 11 percent, in 2013, by 10 percent, and in 2014, by a shocking 15 percent. There was not a single demographic that escaped these increases. Males and females, LGBT persons and heterosexuals, and even newborns experienced increases in syphilis.

In fact, between 2012 and 2014, congenital syphilis, which can be a disabling, and often life-threatening infection for infants, increased by 38 percent, to the highest rate in almost 15 years. While syphilis is primarily a sexually transmitted disease, it may be passed on by an infected woman during pregnancy. Passing on the infection during gestation or at birth may lead to serious health problems including premature birth, stillbirth, and in some cases, death shortly after birth. Sadly, untreated syphilis in pregnant women results in infant death in up to 40 percent of cases. Untreated infants who survive will often develop problems in multiple organs, including the brain, eyes, ears, heart, skin, teeth, and bones.

Increases have also occurred in cases of ocular syphilis that are resulting in significant eyesight and vision problems, including instances of complete and irreversible blindness. Between December 2014 and March 2015, 12 cases of ocular syphilis were reported from two major cities, San Francisco and Seattle. Subsequent case finding indicated more than 200 cases over the past two years from 20 states.

Strained Public Health Infrastructure

Responding to these ever-increasing STDs is a strained public health infrastructure. Since 2003, federal investments in STD prevention have been stagnant when adjusted for inflation. In fact, due to mostly flat funding, the real buying power of federal funding has plummeted 38 percent. State, territorial and local health departments across the country that

spearhead STD prevention and control have charged forward with STD prevention and control, but the weight of the work is being overburdened by a lack of national investment in these efforts and in public health.

According to Trust for America's Health, combined federal, state and local public health spending is currently below pre-recession levels. Adjusting for inflation, public health spending is currently 10 percent lower in 2013 than in 2009. At the same time, state and local investments, largely as a result of the recession budget crunch, have equally collapsed. At the height of the recession, the National Association of County and City Health Officials reports that up to 45 percent of local health departments reported budget cuts; one in four is still affected by budget cuts today. Since 2008, 51,700 jobs have been lost at local health departments. As a result, when it comes to STDs, we are in the midst of true genuine crisis.

A New Response is Needed

Due to these infrastructure losses, our STD public health infrastructure is in a state of crisis and additional resources are needed to combat our growing STD epidemics. If fully funded, this request would go to two distinct but complimentary needs, which are outlined below.

1. Additional Workforce Needs: $5.1 million

- Funding would be disseminated to public health departments for more boots on the ground.
- This could include trained epidemiology staff, more staff to ensure positive cases are tracked down and treated, or medically trained staff to best respond to each health department's needs for dealing with their epidemics.

2. Program Science Activities: $3 million

- Our current system of prevention and control careens from one emergency outbreak to another, and this cannot continue.
- Improved data is needed to show, empirically, what is causing this surge in STDs and which evidenced-based interventions work to best to reduce STDs in the U.S.
- Additional program science evidence is also needed to better understand how to reach communities hardest hit by STD increases.
- This would result in evidence-based interventions that can be scaled up across the country to respond to these ever-rising rates.

In fiscal year 2017 funding, please support an urgent funding increase of $8.1 million to the Division of STD Prevention to ensure those on the front lines of STD prevention have funding to respond to the rising rates of all STDs, particularly syphilis, and prepare for other foreseen outbreaks. For more information, please contact the National Coalition of STD Director's Director of Policy and Communications, Stephanie Arnold Pang at sarnold@ncsddc.org or 202-842-4660.

Monika Johnson Hostler
President, Board of Directors
National Alliance to End Sexual Violence

Testimony Presented for the Record

United States House of Representatives
Committee on Appropriations
Subcommittee on Labor, Health and Human Services, Education, and Related Agencies

April 15, 2016

Thank you for the opportunity to present outside written testimony to the U.S. House of Representatives, Committee on Appropriations' Labor, Health and Human Services, Education, and Related Agencies Subcommittee. I am Monika Johnson Hostler, President of the Board of Directors of the National Alliance to End Sexual Violence (NAESV), representing 56 state and territorial sexual assault coalitions and more than 1300 local rape crisis centers. I am respectfully requesting FY 2017 Department of Health and Human Services federal funding to support comprehensive rape prevention and education and direct services for victims of sexual violence. Specifically, NAESV is urging Congress to provide $50 million, including at least $5.6 million in additional program dollars to meet the local demand for prevention and education and the implementation of evidence-based strategies through the Rape Prevention & Education program (RPE) in the Centers for Disease Control and Prevention's (CDC) National Center for Injury Prevention and Control, Intentional Injury Prevention budget. In addition, NAESV is requesting level funding of $160 million for the Preventive Health and Health Services Block Grant, which includes a $7 million set-aside for rape victim services and prevention, in CDC's State, Tribal, Local and Territorial Support program budget. Together, we must make our communities safer.

One in five women has been the victim of rape or attempted rape. Nearly one in two women has experienced some form of sexual violence, and one in five men has experienced a form of sexual violence other than rape in their lifetime. The CDC National Intimate Partner and Sexual Violence Survey study confirmed that the impacts of sexual violence on society are enormous. Over 80% of women who were victimized experienced significant short and long-term impacts related to the violence such as Post-Traumatic Stress Disorder (PTSD), injury (42%) and missed time at work or school (28%). The CDC report also shows that most rape and partner violence is experienced before the age of 24, highlighting the importance of preventing this violence before it occurs.

The 2015 Rape Crisis Center Survey, distributed by NAESV, demonstrated that almost half of rape crisis centers had to decrease the number of public awareness or prevention services due to insufficient funding while over 1/3 of rape crisis centers could not provide counseling services within one month of a request. High profile cases of sexual assault on campuses, our military bases, military academies, and by celebrities and professional athletes have resulted in unprecedented media attention. This has also resulted in a tremendous increase in sexual assault survivors seeking assistance from local rape crisis centers, as well as an increase in educators and community organizations requesting prevention and training services. The media attention

certainly points to the need for comprehensive community responses to sexual violence like those funded through the CDC Rape Prevention and Education program and the Preventive Health and Health Services Block Grant. As you begin the FY 2017 appropriations process, please fund these programs so critically important to the prevention and response to sexual assault.

Rape Prevention and Education (RPE) – The National Alliance to End Sexual Violence urges Congress to appropriate $50 million, including at least $5.6 million in additional program dollars to meet the demand for prevention and education and the implementation of evidence-based strategies. Funding for RPE through the CDC Injury Center's budget for Intentional Injury Prevention strengthens sexual violence prevention efforts at the state and local levels. The RPE program provides formula funding to every state and territory to raise awareness of the problem of sexual assault, support efforts to prevent first-time perpetration and victimization, and brings together diverse partners to develop, implement and evaluate statewide sexual assault prevention plans. The RPE program engages boys and men as partners, supports interdisciplinary research collaborations, fosters cross-cultural approaches to prevention, promotes healthy relationships, and funds the critically important National Sexual Violence Resource Center. High profile cases and the focus on campuses have increased the demand for prevention and education in middle and high schools, as well as the community, beyond the current capacity of state sexual assault coalitions and local rape crisis centers. Program funding must be increased in this unprecedented time of opportunity. With FY 2013 funding, the program reached over 2 million students, answered 340,000 hotline calls, and trained nearly 160,000 professionals about sexual abuse.

Program Evaluation: There is a need to increase the evidence base for sexual violence prevention. However, those efforts should be funded by additional funding – not from program funds to states and local rape crisis centers. We support the CDC's proposed budget request for evaluation funds, but not at the expense of program funding. We do not want program funds diverted from the communities at a time when demand and opportunity for prevention and education, as well as services, is increasing at such a rapid rate. Increased program funding is required to avoid critical shortfalls at a time of increased awareness and opportunity for prevention and education.

In FY 2016, CDC plans to fund a maximum of five academic or research institutions to evaluate prevention strategies that are being used in communities to address immediate and divergent needs in the field, but have limited research evidence to show effectiveness in reducing rates of sexual violence. In order to build RPE program evaluation capacity at the state health department level, CDC will fund state-wide evaluations to better assess how RPE prevention efforts are impacting health outcomes, sexual violence risk and protective factors, and rates of sexual violence. Efforts will be made to improve data collection and performance measures. Additional research will be done to build evaluation capacity of RPE grantees and identify community developed prevention strategies ready for rigorous evaluation. Within the past year, CDC decided to make "state level evaluation" mandatory despite many states starting local, regional or targeted evaluation efforts. It was the CDC's stated perspective that this would be "less labor intensive." However, this strategy forced everyone down one path, without a recognition of the work and progress that was currently underway in many states, nor of each

state's individual goals, projects or bandwidth to accomplish the work. Strong partnerships between evaluators and community-based sexual assault programs and state sexual assault coalitions engaged in prevention are essential for success.

In FY 2015, CDC funded two awards to evaluate strategies that engage boys/men for their impact on rates of sexual violence perpetration. An additional two research grants were awarded to focus on rigorously evaluating primary prevention strategies for dating and sexual violence among youth. One grant focuses on bystander prevention while the second grant examines a program which trains athletic coaches to modify gender norms that contribute to dating and sexual violence and to promote bystander intervention skills. Research results and recommendations are pending.

Preventive Health & Health Services Block Grant (PHHSBG) – We are very grateful for the FY 2015 and FY 2016 funding of $160 million enacted by Congress and disappointed with the Administration's efforts to eliminate the program which provides much needed resources to communities. The Public Health Service Act of 2010 authorizes the block grant and CDC moved its administration from Chronic Disease to State, Tribal, Local and Territorial Support. Congress provided a rape set-aside provision which guarantees at least $7 million for rape services and prevention. Please retain the block grant funding that supports local rape crisis centers providing services, statewide training and technical assistance to increase capacity to assist rape victims and prevent future victimization. Maximum funding is requested.

We must have the resources to meet the education and prevention needs in the community. Victims deserve support, our young people deserve to grow up safely, and research tells us that appropriate and early intervention and prevention can mitigate the costs and consequences of sexual violence and prevent that violence from occurring in the first place. The best way to prevent victimization is to prevent first time perpetration. The best way to convict a rapist is to support and advocate for the victim, obtain evidence and provide assistance and training to law enforcement. At this time of increased media attention, increased demand for services, increased demand for education in the schools and among community organizations, now is the best time for the implementation of community based prevention strategies.

Thank you for the opportunity for the National Alliance to End Sexual Violence to present testimony for the record as the House Committee on Appropriations Subcommittee on Labor, Health and Human Services, Education, and Related Agencies begins the process to prepare the FY 2017 Appropriations bill. If we can provide further information, please contact me at (919) 871-1015, monika@nccasa.org and www.endsexualviolence.org, or Terri Poore, NAESV Public Policy Director, at (850) 228-3428 or terri@endsexualviolence.org, National Alliance to End Sexual Violence, 1129 20th Street, NW, Suite 801, Washington, DC 20036.

Written Testimony

FY17 Funding: Older Americans Act

Prepared for presentation to the
U.S. House Appropriations Subcommittee on
Labor, Health & Human Services, Education, and Related Agencies

Submitted By:

Beth Truett
CEO/President
Oral Health America
180 North Michigan Avenue, Suite 1150, Chicago, IL 60601
www.oralhealthamerica.org • (312) 836-9900 • beth@oralhealthamerica.org

April 15, 2016

Mr. Chairman, Ranking Member, and distinguished Members of the Subcommittee, **Oral Health America (OHA),** a leading organization dedicated to changing lives by connecting communities with resources to drive access to care, increase health literacy and advocate for policies that improve overall health through better oral health for all Americans, especially those most vulnerable; is requesting FY2017 funding for all programs administered by the **Older Americans Act (OAA)** (U.S. Department of Health and Human Services, Administration on Aging) be restored to at least FY2010 levels. Of particular interest to OHA is to ensure ***Title III-D, Disease Prevention and Health Promotion***, is restored to **at least $21,000,000** because of the cost-effectiveness that health education, health promotion, and disease prevention programs provide to the system. Since FY2012, Title III-D funding has remained stagnant at $19,848,000.

The OAA provides federal programs that serve to meet the needs of millions of older Americans. We understand the United States continues to operate amid a challenging budgetary environment. However, OHA believes that proper federal investment in the OAA is critical to keep pace with the rate of inflation and to meet the needs of this ever-growing segment of the population through the multitude of services the OAA provides. Simply stated, proper investment in OAA saves taxpayer dollars. This is especially evident when it comes to health services. Health services that emphasize prevention and promotion will help to reduce disease, leading to the improvement of the overall health and well-being of America's older adults and resulting in the reduction of premature and costly medical interventions. OHA strongly contends that one's health and overall well-being begins with proper oral health. This core belief applies throughout the lifespan and especially with older adults.

Background

The population of the United States is aging at an unprecedented rate. Older adults make up one of the fastest growing segments of the American population. In

2009, 39.6 million seniors were U.S. residents. This aging cohort is expected to reach 72.1 million by 2030 -- an increase of 82 percent.[i]

The oral health of older Americans is in a state of decay. The reasons for this are complex. Limited access to dental insurance, affordable dental services, community water fluoridation, and programs that support oral health prevention and education for older Americans are significant factors that contribute to the unmet dental needs and edentulism among older adults, particularly those most vulnerable. While improvements in oral health across the lifespan have been observed in the last half century, long term concern may be warranted for the 10,000 Americans retiring daily, as it is estimated that only 9.8 percent of this "silver tsunami"—baby boomers turning age 65 -- will have access to dental insurance benefits.[ii]

Dental Health and Disparities: Oral health data reveals that many older adults experience adverse oral health associated with chronic and systemic health conditions. For example, associations between ***heart disease, periodontitis and diabetes have emerged in recent years, as well as oral conditions such as xerostomia associated with the use of prescription drugs.***[iii] [iv] Xerostomia, commonly known as dry mouth, contributes to the inception and progression of dental caries (cavities). For older Americans, the occurrence or recurrence of dental caries coupled with an inability to access treatment may lead to significant pain and suffering along with other detrimental health effects.

These oral conditions disproportionately affect persons with low income, racial and ethnic minorities, and those who have limited or no access to dental insurance. Older adults with physical and intellectual disabilities and those persons who are homebound or institutionalized are also at greater risk for poor oral health.[v]

As examples of these disparities, older African American adults are 1.88 times more likely than their white counterparts to have periodontitis;[vi] low-income older adults suffer more than twice the rate of gum disease than their more affluent peers (17.49 verses 8.62 respectively); and Americans who live in poverty are 61 percent more likely to have lost all of their teeth when compared to those in higher socioeconomic groups.

Aging in Place: Despite these existing conditions, recent dental public health trends demonstrate that as the population at large ages, older Americans are increasingly retaining their natural teeth.[vii] Today, many older adults benefit from healthy aging associated with the retention of their natural teeth, improvements in their ability to chew, and the ability to enjoy a variety of food choices not previously experienced by earlier generations of their peers.

Nearly 90 percent of older adults want to stay in their own homes as they age, often referred to as "Aging in Place." Today's older adults are living more independently than previous generations. In fact, only 9 percent of older adults live in a long term care setting. Maintaining a healthy mouth is one of the keys to independence as we age, however resources for oral health remain conspicuously absent from home and community-based services and are largely disconnected and difficult to access.

Oral Care Provider Issues: Although a growing number of older Americans need oral healthcare, the current workforce is challenged to meet the needs of older adults. The current dental workforce is aging, and many dental professionals will retire within the next decade. A lack of geriatric specialty programs complicates this problem, and few practitioners are choosing geriatrics as their field of choice.

While these trends are favorable, adverse oral health consequences are emerging. Due to reasons stated in this report, together with increased demand for services, lack of access to dental benefits through Medicare, increased morbidity and mobility among older adults, and reduced income associated with aging and retirement, many older Americans are unable to access oral health care services. As a result, many older adults who have retained their natural teeth are now experiencing dental problems.

Older Adults' Oral Health in State of Decay

OHA's 2016 ***A State of Decay***, Vol. III report is a state-by-state analysis of oral healthcare delivery and public health factors impacting the oral health of older adults. The report revealed more than half of the country received a "fair" or "poor" assessment when it comes to minimal standards affecting dental care access for older adults. The top findings of the report were:

- **Tooth loss continues to be a signal of suboptimal oral health.** There are eight states with a 20% or more rate of edentulism, with West Virginia still notably having an older adult population that is 33.6% edentate.
- **Communities without fluoridated water ignore opportunities for prevention.** While states have increased the rates of communities with fluoridated water since 2010, five states (10%) still have 60% or more of their residents living in communities unprotected by fluoridated water. Hawaii (89.2%) and New Jersey (85.4%) have the highest rates of unprotected citizens, representing an unnecessary public peril 70 years after Community Water Fluoridation (CWF) was introduced and since named a public health best practice.
- **Persistent shortage of oral health coverage.** Sixteen percent (8 states) cover no dental services through Medicaid and only four states (8%) cover the maximum possible dental services in Medicaid.
- **Critical lack of a strategic plan to address the oral health of older adults.** **Eighty**-four percent (42 states) lack a State Oral Health Plan that both mentions older adults and includes SMART objectives. Of the 42 states, 14 lack any type of State Oral Health Plan.
- **Inadequate surveillance of the oral health condition of older adults persists.** Forty-six percent (23 states) have never completed a Basic Screening Survey of older adults and have no plan to do so.

Moreover, poor oral health has substantial financial implications. For example, in 2010 alone, between $867 million and $2.1 billion was spent on emergency dental procedures.[viii] When compared to care delivered in a dentist's office, hospital treatments are nearly ten times more expensive than the routine care that could have prevented the emergency. This places a costly yet avoidable burden on both the individual and the health institutions that must then bear the expense.

In sum, oral health and access to preventive care significantly impact overall health and expenditure, yet are difficult to maintain—particularly for older adults—in the nation's present context of support systems and healthcare.

How OHA Empowers Older Adults to Meet their Oral Health Needs

Oral Health America's Wisdom Tooth Project® aims to change the lives of older adults especially vulnerable to oral disease. Its goal is to educate Americans about the oral health needs of older adults, connect older adults to local resources, and to advocate for policies that will improve the oral health of older adults. The Wisdom Tooth Project achieves these goals through five strategies: our web portal, regional symposia, communications, advocacy and demonstration projects.

In addition to the ***A State of Decay*** report referenced above, a vital component of the Wisdom Tooth Project is Toothwisdom.org, which is a first-of-its-kind website created to connect older adults and their caregivers to local care and education around the oral health issues they face, the importance of continuing prevention as we age, and the overall impact of oral health on overall health.

Importance of OAA Reauthorization to Oral Health of Older Adults

Recognizing this current state of oral health among older adults, Oral Health America vigorously applauds Congress for passing the bipartisan-supported Older Americans Act reauthorization, S.192. The bill includes—for the first time—a small provision that allows the Aging Network to use funds they receive for disease prevention and health promotion activities to conduct oral health screenings. Preventive dental care that can be provided through oral health screenings can head off more expensive dental work and help prevent severe diseases. Unfortunately, dentists see older adults everyday living with infection and pain that could be easily avoided with proper care that these screenings could provide. Although the oral health screenings provision would not require new or additional funding under Title III-D, Disease Prevention and Health Promotion Services, restoring funding to at least FY2010 levels would greatly assist the Aging Network to conduct the screenings. More succinctly, the reauthorization bill recognizes the importance of oral health and its role in disease prevention. We view this as a step toward improving the oral—and overall—health of older adults and call for the bill's passage.

RECOMMENDATION

It is evident the United States' health care system is woefully unprepared to meet the oral health challenges of a burgeoning population of older adults with special needs, chronic disease complications, and a growing inability to access and pay for dental services. However, the benefits of proper oral hygiene and routine care for older adults to our nation's healthcare system and economy are also quite clear. Through OHA's Wisdom Tooth Project, OHA aspires to change the lives of older adults especially vulnerable to oral disease. OHA views proper funding of the Older Americans Act as a crucial federal investment vehicle to advance health promotion and disease prevention. Therefore, OHA recommends the Subcommittee to restore FY2017 funding for all OAA programs to at least FY2010 levels, and moreover, to ensure *Title III-D, Disease Prevention and Health Promotion*, is restored to **at least $21,000,000** because of the cost-effectiveness that health education, health promotion, and disease prevention programs provide to the system.

Thank you for the opportunity to present and submit our written testimony before the Subcommittee.

---

[i] Administration on Aging. (2013). *Aging Statistics*. Retrieved from http://www.aoa.gov/Aging_Statistics/

[ii] Consumer Survey, National Association of Dental Plans. 2012.

[iii] Ira B. Lamster, DDS, MMSc, Evanthia Lalla, DDS, MS, Wenche S. Borgnakke, DDS, PhD and George W. Taylor, DMD, DrPH. (2008). Journal of the American Dental Assocation.

[iv] Fox, Philip C. (2008). *Xerostomia: Recognition and Management*. Retrieved from: http://www.colgateprofessional.com.hk/LeadershipHK/ProfessionalEducation/Articles/Resources/profed_art_access-supplement-2008-xerostimia.pdf

[v] U.S. Department of Health and Human Services. (2000). *Oral Health in America: A Report of the Surgeon General*. Retrieved from http://silk.nih.gov/public/hck1ocv.@www.surgeon.fullrpt.pdf

[vi] Borrel, L.N., Burt, B.A., & Taylor, G.W. (2005, October). Prevalence and Trends in Periodontitis in the USA: from the NHANES III to the NHANES, 1988 to 2000. *Journal of Dental Research,84*(10). Retrieved from http://jdr.sagepub.com/content/84/10/924.abstract

[vii] Dolan, T. A., Atchison, K., & Huynh, T. N. (2005). Access to Dental Care Among Older Adults in the United States. *Journal of Dental Education, 69*(9), 961-974. Retrieved from http://www.jdentaled.org/content/69/9/961.long

[viii] Wall, Thomas and Nasseh, Dr. Kamyar, "Dental-Related Emergency Department Visits on the Increase in the United States," Health Policy Institute, ADA, May 2013, http://www.ada.org/~/media/ADA/Science%20and%20Research/HPI/Files/HPIBrief_0513_1.ashx

American Association of Colleges of Pharmacy AACP
Discover · Learn · Care: Improve Health
1727 King Street · Alexandria, VA 22314
p: 703-739-2330 · f: 703-836-8982 · www.aacp.org

Submitted for the Record to the House Committee on Appropriations
Subcommittee on
Labor, Health and Human Services, Education, and Related Agencies
April 14, 2016

Testimony Addresses the US Department of Health and Human Services & the US Department of Education

William Lang, Senior Policy Advisor
Phone: 703-739-2330 Email: wlang@aacp.org

The American Association of Colleges of Pharmacy (AACP) is pleased to submit this statement for the record regarding FY2017 funding. The 135 accredited pharmacy schools are engaged in a wide range of programs funded by the agencies of the Department of Health and Human Services (HHS) and the Department of Education. Recognizing the difficult task of balancing needs and expectations with fiscal responsibility, AACP respectfully requests that the following agencies and programs be funded appropriately as you undertake your deliberations:

- Health Resources and Services Administration (HRSA) - $7.48 billion
  - Title VII & VIII - $524 million
- Agency for Healthcare Research and Quality (AHRQ) - $364 million
- Centers for Disease Control and Prevention (CDC) – $7.8 billion
  - National Center for Health Statistics (NCHS) - $172 million
- National Institutes of Health (NIH) - $34.5 billion

In addition, AACP respectfully requests that the Fund for the Improvement of Post-Secondary Education (FIPSE) be funded at $100 million and that the maximum Pell grant appropriated discretionally be maintained at $4860.

US DEPARTMENT OF HEALTH AND HUMAN SERVICES - Health Resources and Services Administration (HRSA) AACP supports the Friends of HRSA recommendation of $7.48 billion for HRSA in FY17. Dr. Nathaniel Rickles from Northeastern University Bouve College of Health Sciences School of Pharmacy received $161,769 from HRSA to research interprofessional geriatric education for team based care. Faculty at schools of pharmacy are integral to the success of many HRSA programs conducting research on rural health delivery via telemedicine. Schools of pharmacy are supported by HRSA to operate some of the 55 **Poison Control Centers.** AACP supports the **Bureau of Health Workforce (BHW)** and the **National Center for Health Workforce Analysis (NCHWA).** Through the Pharmacy Workforce Center, AACP joins HRSA-funded efforts to compile national health workforce statistics to better inform future health professions workforce needs in the United States. **AACP supports the Health Professions and Nursing Education Coalition (HPNEC) recommendation of $524 million for Title VII and VIII programs in FY16.** AACP member institutions are active participants in BHW programs. Schools of pharmacy participate in Title VII programs, including Geriatric Education Centers and Area Health Education Centers (AHEC). These community-based, interprofessional programs are **essential** for supporting innovative educational models addressing national issues at the local level through team-based, patient-centered care. They serve as valuable experiential education sites for student

pharmacists and other health professions students. Pharmacy schools are eligible to participate in the **Centers of Excellence** program and the **Scholarships for Disadvantaged Students** program, to increase the number of underserved individuals attending health professions schools and increase minority health workforce representation. Colleges of pharmacy, including Xavier University of Louisiana, develop and maintain centers of excellence in diversity supported by HRSA Centers of Excellence grants.

Agency for Healthcare Research and Quality (AHRQ) - **AACP supports the Friends of AHRQ recommendation of $375 million in budget authority for AHRQ programs in FY17.** Pharmacy faculty are strong partners with the Agency for Healthcare Research and Quality (AHRQ). Drs. Margie E. Snyder, Karen Hudmon and Michael Murray received $144,197 from PHS-AHRQ for optimizing medication therapy management for chronically ill Medicare Part D beneficiaries.

Centers for Disease Control and Prevention (CDC) - **AACP supports the CDC Coalition's recommendation of $7.8 billion for CDC core programs in FY17 and the Friends of NCHS recommendation of $172 million for the National Center for Health Statistics.** Information from the NCHS is essential for faculty engaged in health services research and for the professional education of the pharmacist. The educational outcomes for pharmacy graduates include those related to public health. The opportunity for pharmacists to identify potential public health threats through regular interaction with patients provides public health agencies with on-the-ground epidemiologists providing risk identification measures when patients seek medications associated with preventing and treating travel-related illnesses. Pharmacy faculty are engaged in CDC-supported research and activities including delivery of immunizations, integration of pharmacogenetics in the pharmacy curriculum, inclusion of pharmacists in emergency preparedness, and the Million Hearts campaign. Dr. Johnnye Lewis at the University of New Mexico received $1,000,000 to study uranium exposure in the Navajo nation.

National Institutes of Health - **AACP supports the Adhoc Group for Medical Research recommendation of at least $34.5 billion for NIH funding in FY17.** Pharmacy faculty are supported in their research by nearly every institute at the NIH. The NIH-supported research at AACP member institutions spans the full spectrum from the creation of new knowledge through the translation of that new knowledge to providers and patients. In fiscal year 2014, pharmacy faculty researchers received nearly $343 million in grant support from the NIH. Academic pharmacy sustains a strong commitment to increasing the number of biomedical researchers. Dr. Jim Wang at the University of Illinois received $404,011 to study protein kinase mechanisms for chronic pain in sickle cell disease.

US DEPARTMENT OF EDUCATION - The Department of Education supports the education of healthcare professionals by assuring access to education through student financial aid programs, educational research allows faculty to determine improvements in educational approaches; and the oversight of higher education through the approval of accrediting agencies. **AACP supports the Student Aid Alliance's recommendations to maintain the discretionary contribution to the $4860 maximum Pell grant.** Admission to a pharmacy professional degree program requires at least two years of undergraduate preparation. Student financial assistance programs are

essential to assuring student have access to undergraduate, professional and graduate degree programs. **AACP recommends a funding level of at least $100 million for the Fund for the Improvement of Post-Secondary Education** (FIPSE) as this is the only federal program that supports the development and evaluation of higher education programs that can lead to improvements in higher education quality.

Testimony for the Record
submitted to the
House Committee on Appropriations
Subcommittee on Labor, Health and Human Services, Education, and Related Agencies
April 15, 2016

My name is Maria Vargas. I serve as Chair of the Social Security Vocational Expert (SSVE) Section of the International Association of Rehabilitation Professionals (IARP). I am writing to request that the Subcommittee provide adequate funding in the Social Security Administration's Limitation on Administrative Expenses to assure that SSVEs are paid a fair market rate for their services.

IARP's SSVE Section is the only professional organization section with a focus on serving SSVEs. Our more than 600 members are experienced vocational rehabilitation professionals who assist individuals with disabilities to find and maintain competitive employment across the country. We are writing to express our extreme concern about the integrity and the future of the Social Security disability determination process. We request that the Subcommittee address an urgent issue that is affecting the ability of both disability claimants and taxpayers to continue to rely on an accurate, informed determination process going forward: compensation rates for SSVE services that have remained virtually unchanged for 37 years.

Like most VR professionals, SSVEs are small-business owners or employees of local small businesses. We work directly with clients, we testify in court, and we consult on workers compensation and private-insurance cases. In addition, on certain days each month, we offer our expertise to the Social Security Administration (SSA) as independent contractors providing vocational expert testimony in Social Security Disability hearings. Last year, VEs offered expert testimony in 800,000 of the one million hearings held.

As SSVEs, we provide information concerning the existence of jobs in the national economy as well as an individual's ability to perform job functions based on work capacity. Administrative Law Judges draw on our impartial expert opinions to provide a factual basis for determining whether a claimant meets Social Security's strict definition of disability and therefore is eligible to receive disability benefits. This is a crucial component of the disability-determination process that helps to assure that ALJs reach a correct decision that is supported by evidence.

And yet, the rate SSA pays for SSVE services through a fixed-rate Blanket Purchase Agreement has remained essentially unchanged for 37 years! In May 2012, the SSA Inspector General in an audit report (A-12-11-11124) raised concerns about the quality and availability of SSVEs and recommended that SSA conduct a compensation study to determine whether SSVE fees are reasonable and consistent with VE fees paid in the national economy or by other government entities. Despite the IG's concerns and recommendations, SSA has declined to conduct any market research to establish fair market value, and recently extended the current BPA through March of 2018 without any rate increase. This rate is less than half of what VEs earn on average

for case management and less than one-third of what we are paid for other VE testimony. It is affecting our ability, and that of other experienced, qualified SSVEs, to continue to provide VE services to SSA in the future.

Current evidence suggests that fewer practicing vocational rehabilitation professionals are willing to take time out of their schedules to participate in SSA disability hearings. We also are concerned that a growing number of SSVEs are no longer actively providing vocational rehabilitation services, but instead are using their work as SSVEs to supplement their retirement incomes. Of even greater concern, anecdotal evidence suggests that some individuals who have neither the education nor the professional experience to qualify as VEs are none-the-less receiving BPAs and participating in hearings.

SSA has indicated that it plans to move to a competitive bidding process for VE services beyond 2018. While we have significant reservations about this new approach, our immediate concern is that even two more years at the current, 37-year-old rates could have a devastating impact on the integrity of the disability-determination process. We urge Congress to direct SSA to act now to conduct a compensation study of VE rates as recommended by the IG, and then promptly take steps to adjust its rates to reflect the results of that study. We respectfully request that Congress provide adequate funding in SSA's Limitation on Administrative Expenses to compensate SSVEs at a fair market rate.

Thank you for the opportunity to provide our comments to the Subcommittee.

Testimony on behalf of the
Population Association of America/Association of Population Centers
Regarding the Fiscal Year 2017 Appropriation for the
National Institutes of Health, National Center for Health Statistics, and Bureau of Labor Statistics
Submitted to the
House Committee on Appropriations
Subcommittee on Labor, Health and Human Services and Education
By Mary Jo Hocksema, Director, Government and Public Affairs
Population Association of America/Association of Population Centers
maryjo@popassoc.org, 301-565-6710 ex. 1006

Introduction

Thank you, Chairman Cole, Ranking Member DeLauro, and other distinguished members of the Subcommittee, for this opportunity to express support for the National Institutes of Health (NIH), National Center for Health Statistics (NCHS), and Bureau of Labor Statistics (BLS). These agencies are important to the members of the Population Association of America (PAA) and Association of Population Centers (APC) because they provide direct and indirect support to population scientists and the field of population, or demographic, research overall. In FY 2017, we urge the Subcommittee to adopt the following funding recommendations: $34.5 billion for the NIH, consistent with the level recommended by the Ad Hoc Group for Medical Research; $170 million for the NCHS, consistent with the Friends of NCHS recommendation; and $640.9 million, for the BLS, consistent with the Administration's request.

The PAA and APC are two affiliated organizations that together represent over 3,000 social and behavioral scientists and approximately 40 population research centers nationwide that conduct research on the implications of population change. Our members, which include demographers, economists, sociologists, and statisticians, who conduct scientific research, analyze changing demographic and socio-economic trends, develop policy recommendations, and train undergraduate and graduate students. Their research expertise covers a wide range of issues, including adolescent health and development, aging, health disparities, retirement, and labor. Population scientists compete for discretionary grant funding from the NIH and rely on data from the nation's statistical agencies to conduct research and research training activities.

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 extramural population research programs primarily through the National Institute on Aging (NIA) and the National Institute of Child Health and Human Development (NICHD).

PAA and APC thank the subcommittee for supporting a $2 billion increase for the NIH in Fiscal Year 2016 and look forward to working with the Congress to ensure NIH can continue to receive sustainable, steady increases in Fiscal Year 2017 and beyond.

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 addition to supporting an impressive research portfolio, that includes the prestigious Centers on the Demography and Economics of Aging, the NIA BSR Division also supports several large, accessible surveys. For example, the Health and Retirement Study (HRS), provides unique information about economics transitions in work, income, and wealth, allowing scientists to study how the domains of family, economic resources, and health interact. Since 1992, the HRS has collected data, including, most recently, biomarkers, from a representative sample of more than 27,000 Americans over the age of 50 every two years. These data are accessible to researchers worldwide and have informed numerous scientific findings.

In 2015, NIA grantee using vital statistics data as well as data from the HRS, published findings confirming rising mortality rates among middle aged, white, non-Hispanic Americans. This change reversed decades of progress in mortality and was unique to the United States. The study found increasing death rates resulted largely from "diseases of despair" - drug and alcohol poisonings, suicide, and chronic liver diseases and cirrhosis. The most dramatic increases in mortality occurred among the poorly educated. The findings point to alarming trends in populations previously thought to be healthy and underscore the need for broad public health strategies to combat their causes.

With additional support in FY 2017, the Institute can sustain and expand its investment in population aging research, including contributing to the Institute's efforts to address the scourge of dementia and Alzheimer's disease. The BSR division is also eager to support research and data collection on the causes of widening disparities in health and longevity at older ages, and the role of social factors, such as education and income, in the health and well-being of older people. As members of the Friends of NIA, we urge the Committee to provide the NIH with an additional $500 million in FY 2017 to support aging research activities not only at the NIA, but also across the agency.

Eunice Kennedy Shriver National Institute on Child Health and Human Development

Since 1968, NICHD has supported research on population processes and change. This research is housed in the Institute's Population Dynamics Branch, which supports research and research training in demography, reproductive health, and population health and funds major national studies that track the health and well-being of children and their families from childhood through adulthood. These studies include Fragile Families and Child Well Being, the first scientific study to track the health and development of children born to unmarried parents, and the National Longitudinal Study of Adolescent Health (Add Health), tracing the effects of childhood and adolescent exposures on later health. The Add Health study received a 2016 Golden Goose Award, recognizing its significant and unique scientific contributions and innovations.

In 2015, scientists, using data from these large-scale data sets published numerous findings. For example, scientists, used data from the Fragile Families and Child Wellbeing Survey, found a negative association between father engagement and children's behavioral problems, independent of the mother's characteristics and her level of engagement. Using data from the Add Health study, scientists determined that social relationships affect individual's physical health, including chronic disease and longevity. (http://www.populationassociation.org/wp-content/uploads/PAAAPC-Advances-in-Population-Research.pdf).

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 FY 2017, the Institute will be able to maintain its strong commitment to these centers of research excellence. As members of the Friends of NICHD, PAA and APC request that the Institute receive a funding level of $1.441 billion in FY 2017.

National Center for Health Statistics

The National Center for Health Statistics (NCHS) is the nation's principal health statistics agency, providing data on the health of the U.S. population and backing essential data collection activities. Most notably, 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 a number of complex large surveys to help policy makers, public health officials, and researchers understand the population's health, influences on health, and health outcomes. These surveys include the National Health and Nutrition Examination Survey and National Survey of Family Growth. The wealth of data NCHS collects makes the agency an invaluable resource for population scientists.

In recent years, NCHS has made significant progress toward modernizing the NVSS, moving many states from paper-based to electronic filing of birth and death statistics and expediting the release of these data to the user community. However, persistent flat funding levels in recent years, and the loss of funds from the Prevention and Public Health Fund, are hampering the agency's ability to enact additional innovations and make necessary survey redesigns and system improvements. That is why as members of the Friends of NCHS, PAA and APC request that NCHS receive $170 million in budget authority in FY 2016, an amount $10 million above the Administration's request. Among other things, NCHS could use this additional money to support ongoing implementation of electronic death records nationwide to provide faster, better vital statistics and to pursue a thoughtful, well-conducted redesign of the National Health Interview Survey.

Bureau of Labor Statistics

BLS produces essential economic information for public and private decision making. Population scientists who study and evaluate labor and related economic policies and programs use its data extensively. The agency also supports the National Longitudinal Studies program and the American Time Use Survey, which are invaluable datasets that the population sciences use to

understand how complex factors, such as changes in work status, income, and education, interact to affect health and achievement outcomes in children and adults.

PAA and APC joins other organizations comprising the Friends of Labor Statistics in thanking the subcommittee for providing BLS with a $17 million increase in FY 2016. However, the agency is still struggling to overcome years of insufficient support. Between FY 2009 and FY 2015, the absolute value and/or the purchasing power of BLS appropriations decreased *every year*. As a result, the agency eliminated several programs in FY 2013 and FY 2014 and in FY 2015 had to rely on a one-time transfer from the Department of Commerce to maintain BLS' Export Price Program. The agency also cut back its rate of replacement of staff and staff training and development to unsustainable levels in 2015.

Given the importance and unique nature of BLS data, we urge the Subcommittee to support the Administration's request, $640.9 million, an increase of $31.9 million above the FY 2016 funding level. This funding would allow BLS to support its core programs and surveys and to conduct other postponed activities, including a supplement to the Current Population Survey and changes to the Consumer Expenditure Survey to support development of a supplemental statistical poverty measure.

Thank you for considering our organization's positions on these agencies under your subcommittee's jurisdiction.

Robert Blancato, National Coordinator
DefeatMalnutrition.Today

Chairman Cole, Ranking Member DeLauro;

I thank you for the opportunity to offer testimony in support of the Department of Health and Human Services' proposed increase of $13.8 million for Older Americans Act Title III(C) senior nutrition programs within the Administration for Community Living. This testimony is on behalf of DefeatMalnutrition.Today, a coalition of 36 community, healthy aging, nutrition, advocacy, health care professional, faith-based, and private sector stakeholders and organizations who share the goals of achieving the recognition of malnutrition as a key indicator and vital sign of adult health and working to achieve a greater focus on malnutrition screening and intervention through regulatory and/or legislative change across the nation's health care system.

Older Americans Act congregate and home-delivered meals programs are provided in every state and congressional district in this nation. Approximately 2.4 million seniors in 2014 received these services.

In FY 2016, Older Americans Act Title III(C) programs received appropriations in the amount of $835 million. Though we are thankful that this represents an increase from FY 2015, unfortunately, this does not keep pace with the rising cost of food, inflation, and the growing numbers of older adults. In fact, the number of older adults receiving meals is shrinking even as the need grows.

The additional $13.8 million in funding for congregate and home-delivered meals will help to counteract inflation and provide more than 1.3 million additional meals. This does not keep up with the growing demand for services, but it would at least prevent further reductions in services.

Studies have found that 50 percent of all persons age 85 and over need help with instrumental activities of daily living, including obtaining and preparing food. Older Americans Act nutrition programs address these concerns. These meal recipients are thus able to remain independent in their homes and communities and are not forced into hospitals or nursing homes due to an inability to maintain a proper diet.

Investing in these programs is cost-effective because many common chronic conditions such as hypertension, heart disease, diabetes, and osteoporosis can be effectively prevented and treated with proper nutrition. The Academy of Nutrition and Dietetics estimates that 87 percent of older adults have or are at risk of hypertension, high cholesterol, diabetes, or some combination of all of these. These seniors need healthy, nutritious meals that may be medically tailored for various conditions, access to lifestyle programs, and nutrition education and counseling to avoid serious medical care.

Older adults who are not receiving proper meals can also become malnourished and undernourished. This makes it harder for them to recover from surgery and disease, makes it more difficult for their wounds to heal, increases their risk for infections and falls, and decreases

their strength that they need to take care of themselves. Malnourished older adults are more likely to have poor health outcomes and to be readmitted to the hospital—their health costs can be 300 percent greater than those who are not malnourished on entry to the health care system.

Keeping older adults well-nourished is essential to keeping them in the community—and studies have consistently found that the highest rates of malnutrition in older adults are found in those who live in care settings as opposed to community-based settings. A Kaiser study found 38 percent prevalence of malnutrition among older adults in their communities, as compared to 91 percent in rehabilitation facilities, 86 percent in hospitals, and 67 percent among those in nursing homes. While direct cause and effect has not entirely been established, it also seems that older adults in the community who are well-nourished are less likely to need to move to these care settings in the first place. We would also note that there is a great need here for tools for providers and practitioners to support the discovery and reduction of senior malnutrition, whether older adults are in care settings or not—38 percent is still an extremely high number of malnourished community-dwelling older adults, considering that fewer than five percent of older adults live in nursing homes.

Access to Older Americans Act meals is essential to keeping these older adults out of costly nursing facilities and hospitals. On average, a senior can be fed for a year for about $1,300. (And, on average, only 37% of this funding comes from the federal government; the rest of the funding for Older Americans Act meals comes from local, state and private sources, making this nutrition program a true public-private partnership.) The cost of feeding a senior for a year is approximately the same as the cost of one day's stay in a hospital or less than the cost of 10 days in a nursing home. The cost savings to Medicare and Medicaid that this creates cannot be over-emphasized. One study estimates that for every dollar invested in the Older Americans Act nutrition programs, Medicaid saves $50.

Further, these services are designed to target those in the "greatest social and economic need," according to the Older Americans Act. According to ACL's studies, approximately two-thirds of home-delivered meal recipients have annual incomes of $20,000 or less. Sixty-two percent of these recipients report that these meals represent at least half their food intake each day. And yet, the Government Accountability Office found that only about nine percent of low-income older adults are even receiving meal services. For a small investment, more at-risk older adults could receive nutritious meals.

For over forty years, the Older Americans Act nutrition programs have been serving older adults who are frail, isolated, and in great need of assistance. With more than 10,000 seniors turning 65 every day, now is the time to provide an even greater investment in these proven and cost-effective programs.

Thank you for your past and future support.

STATEMENT FOR THE RECORD

OF RICHARD E. WARSINSKEY, PRESIDENT

NATIONAL COUNCIL OF SOCIAL SECURITY MANAGEMENT ASSOCIATIONS

Submitted to the House Committee on Appropriations

Subcommittee on Labor, Health and Human Services,

Education, and Related Agencies

Regarding the Social Security Administration's FY 2017 Appropriation

April 15, 2016

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 (FY) 2017 Appropriation. NCSSMA respectfully requests that Congress consider full funding of the President's FY 2017 budget request for SSA, which includes $13.067 billion for SSA's Limitation on Administrative Expenses (LAE) account.

NCSSMA is a membership organization of approximately 3,200 SSA managers and supervisors who provide leadership in nearly 1,250 community-based field offices and teleservice centers throughout the country. We are the front-line service providers for SSA in communities all over the nation. Since the founding of our organization over forty-six years ago, NCSSMA has considered a stable SSA, which delivers quality and timely community-based service to the American public, our top priority. We also consider it paramount to be good stewards of the taxpayers' monies and the Social Security programs we administer.

NCSSMA respectfully requests that Congress consider full funding of the President's FY 2017 budget request, which includes $13.067 billion for SSA's Limitation on Administrative Expenses (LAE) account. This level of funding will allow SSA to improve and modernize customer service, enhance program integrity efforts, deter and detect fraud and errors, and continue to address high volumes of work.

SSA's FY 2016 LAE account funding is $12.162 billion. Although greatly appreciated, this level of funding did not fully cover the agency's inflationary costs. At the same

time, SSA is experiencing an increase in visitors to field offices as members of the baby boom generation retire or file for disability benefits. Nearly 3 million cases are currently pending in the agency's Program Service Centers (PSCs), of which the average case is nearly 4 months old. Many cases involve a dire need for funds, resulting in hardship for the people involved, often including the inability to get Medicare coverage. Over 1.114 million people are waiting for a hearing decision. The number of pending hearings has reached an all-time high. Of serious concern is that this wait is now a record setting 535 days. The processing time for hearings has now increased for 36 consecutive months.

LAE Funding History

FY 2017—SSA Budget Forecast (Dollars in Millions)					
	FY 2013 Enacted	FY 2014 Enacted	FY 2015 Enacted	FY 2016 Enacted	FY 2017 President's Budget
SSA's LAE Funding	$11,046	$11,697	$11,806	$12,162	$13,067

Adequate resources for SSA have a positive impact on delivering vital services to the American public and in fulfilling the agency's stewardship responsibilities. Full funding is critical to maintain staffing in SSA's front-line components, cover inflationary costs, increase deficit-reducing program integrity work, and to address the significantly increased hearings backlog. It is important to note that the FY 2017 budget request includes inflationary increases of over $319 million in fixed costs, including rent, guards, postage, and employee salaries and benefits.

Program Integrity Initiatives

Program integrity initiatives save taxpayer dollars and contribute to reducing the Federal budget and deficit. To address program integrity, the President's FY 2017 SSA budget request includes $1.819 billion for the two most cost-effective tools to reduce improper payments—**Medical Continuing Disability Reviews (CDRs)** and **SSI Redeterminations**. It is important to note that in FY 2015, the same SSA field office employees who answered telephone calls, took initial claim applications, and developed and adjudicated benefit claims, also processed the following program integrity workloads:

- ***799,000 Medical CDRs;*** *and*

- ***2.267 million SSI Redeterminations.***

In FY 2016, SSA projections indicate the agency will complete 850,000 Medical CDRs and 2.522 million SSI Redeterminations. The FY 2017 budget request calls for SSA to process 1,100,000 Medical CDRs, which is an increase of 38% over FY 2015 and 2.822 million SSI Redeterminations, which is an increase of 25% over FY 2015. In order to process this large increase in volume of Medical CDRs and SSI Redeterminations, the field offices and Disability Determination Services (DDSs) will need to have adequate staffing levels in FY 2017, or there could be delays in processing initial disability claims and reconsiderations, and degradation of other services field offices provide.

CDRs conducted in FY 2017 will yield net Federal program savings, on average over the next 10 years, of $8 for every $1 budgeted from dedicated program integrity funding including OADSI, SSI, Medicare and Medicaid program effects. SSI Redeterminations conducted in FY 2017 will yield a return on investment (ROI) averaging about $3 of net Federal program savings over 10 years per $1 budgeted for dedicated program integrity funding, including SSI and Medicaid program effects.

Funding for FY 2017

SSA's FY 2017 budget request includes $301.4 million for over 2,800 work years to handle the additional program integrity workloads, address the massive hearings backlog, increases in other workloads, visitors, and telephone calls in field offices, teleservice centers and Program Service Centers.

The budget request also includes funding of $352.2 million for Information Technology (IT) Modernization. SSA's database systems are over 40 years old and include more than 60 million lines of COBOL coding. Additional IT funding will allow SSA to modernize its computer language, database and infrastructure, including moving its data to the cloud. The budget request also contains a proposal for additional mandatory IT funding through FY 2020. SSA also plans to spend $87 million on cybersecurity.

Again, SSA is challenged by ever-increasing workloads, very complex programs to administer, and increased program integrity work with diminished staffing and resources. With the current fiscal challenges confronting SSA, we encourage Congress to consider changes to the Social Security and SSI programs that have the potential to increase administrative efficiency and lower operational costs.

It is critical SSA receives adequate, yet flexible funding for the LAE account to respond to requests for assistance from the American public, and to fulfill our stewardship responsibilities. SSA's TSCs, hearing offices, PSCs, DDSs, and the nearly 1,250 field offices are in grave need of adequate resources to address their growing workloads. Without adequate funding, SSA will not be able to provide the high-quality customer service Americans deserve, and have paid for. Examples of decreased levels of customer service include inordinately long wait times when visiting SSA field offices or difficulty reaching those same offices by telephone. These very same field offices will also be unable to process program integrity workloads, which save taxpayers billions of dollars and reduce the Federal budget and deficit.

We realize the FY 2017 funding level of $13.067 billion for SSA's LAE account requested above is not insignificant, particularly in this difficult Federal budget environment; however, Social Security serves as the largest and most vital component of the social safety net of America and is facing unprecedented challenges. The American public expects and deserves SSA's assistance and support.

In FY 2017, SSA's programs are projected to pay a combined total of $1.0 trillion in Federal benefits to 68.4 million recipients. Spending on administrative costs for these programs is projected to be only about 1.3% of benefit outlays.

On behalf of NCSSMA members nationwide, thank you for the opportunity to submit this written testimony. We respectfully ask that you consider our comments, and would appreciate any assistance you can provide in ensuring the American public receives the critical and necessary service they deserve from the Social Security Administration.

Submitted By: **Henry Kronenberg, MD, President, Endocrine Society.**
Chief, Endocrine Unit – Massachusetts General Hospital
Professsor of Medicine–Harvard Medical School

FY 2017 SENATE APPROPRIATIONS COMMITTEE PUBLIC TESTIMONY

SUBMITTED BY THE ENDOCRINE SOCIETY

FOR THE SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES, EDUCATION, AND RELATED AGENCIES

ADDRESSING THE NATIONAL INSTITUTES OF HEALTH

The Endocrine Society thanks the Subcommittee for the opportunity to submit the following testimony regarding Fiscal Year (FY) 2017 federal appropriations for biomedical research.

The Endocrine Society is the world's largest and most active professional organization of endocrinologists representing more than 18,000 members worldwide. Our organization is dedicated to promoting excellence in research, education, and clinical practice in the field of endocrinology. The Society's membership includes basic and clinical scientists who receive federal support from the NIH to fund endocrine-related research focusing on, among other challenges, diabetes, cancer, fertility, aging, obesity and bone disease. Our membership also includes clinicians who depend on new scientific advances to better treat and cure their patients' diseases.

100 Years of Endocrine Research: An Investment in the Nation's Health

Sustained investment by the United States federal government in biomedical research has dramatically advanced the health and improved the lives of the American people. The United States' NIH-supported scientists represent the vanguard of researchers making fundamental biological discoveries and developing applied therapies that advance our understanding of, and ability to treat human disease. Their research has led to new medical treatments, saved innumerable lives, reduced human suffering, and launched entire new industries.

Endocrine scientists are a vital component of our nation's biomedical research enterprise and integral to the healthcare infrastructure in the United States. Endocrine Society members study how hormones contribute to the overall function of the body, and how the glands and organs of the endocrine system work together to keep us healthy. Consequently, endocrinologists have a unique approach to and understanding of how the various systems of the human body communicate and interact to maintain health. The areas governed by the endocrine system are broad and essential to overall wellbeing; endocrine functions include reproduction, the body's response to stress and injury, sexual development, energy balance and metabolism, bone and

2055 L Street NW
Suite 600
Washington, DC
20036
T. 202.971.3636
F. 202.736.9705
endocrine.org

muscle strength, and others. Endocrinologists study glands such as the adrenal glands, pancreas, thyroid, and specific sections of the brain, such as the hypothalamus, that control these glands. Endocrinologists also study interrelated systems, for example how hormones produced by fat can influence the development of bone disease.

This year, the Endocrine Society is celebrating its centennial anniversary. The past 100 years have seen hundreds of millions of people helped by the lifesaving treatments and quality care developed through research on hormones funded by the federal government. Some examples include:

- Endocrine scientists discovered and figured out how the hormone insulin works, resulting in treatments for diabetes.
- Endocrine scientists identified and characterized the effects of hormones such as aldosterone on the heart, leading to new treatments for heart failure[1].
- Endocrine scientists discovered that hormones produced by the thyroid gland are necessary for normal cognitive and physical development. Subsequent isolation and characterization of thyroid hormones lead to the development of new, better, and safer therapies for patients with thyroid disorders[2].
- Endocrine scientists have used animal models for obesity to better understand the neuroendocrine basis of obesity, discovering new hormones that regulate energy balance and hunger, such as leptin[3].
- Endocrine scientists improved our understanding of hormone-responsive cancers, such as estrogen-sensitive breast cancer. This knowledge has improved our treatment of certain cancers; tamoxifen, for example, has been used for over 30 years to treat hormone-receptor positive breast cancer by selectively blocking estrogen receptors[4].

The Future of Endocrine Research

More research progress is within reach and could lead to exciting new treatments for serious diseases, for example:

- For patients with diabetes, new treatments could use stem cells derived from skin cells to replace pancreatic cells lost during the progression of the disease; more research has

[1] Richard J. Auchus "Classics in Cardiovascular Endocrinology: Aldosterone Action Beyond Electrolytes" *Endocrinology*, February 2016, 157(2):429 – 431.
[2] Anthony N. Hollenberg "The Endocrine Society Centennial: The Thyroid Leads the Way" *Endocrinology*, January 2016, 157(1):1–3.
[3] Manuel Tena-Sempere "The Endocrine Society Centennial: Genes and Hormones in Obesity… or How Obesity Met Endocrinology" *Endocrinology*, March 2016, 157(3):979 –982.
[4] http://www.cancer.gov/types/breast/breast-hormone-therapy-fact-sheet#q6 Accessed April 11, 2016.

begun to enable the creation of a bionic pancreas that automatically responds to a patient's needs throughout the day.

- New classes of drugs could be developed to combat the obesity epidemic[5].
- Combination approaches that combine chemotherapy with hormonal therapy could improve the treatment of metastatic prostate cancer[6].
- Hormonal therapies could help women with primary ovarian insufficiency restore their bone density to normal levels[7].

As we enter a new era of precision medicine, endocrine scientists are also learning how genetic and biologic markers can be used to understand what causes a disease, the risk factors that predispose to disease, and how patients will respond to a particular treatment. Translating these new discoveries and technologies into personalized patient care offers the possibility of more effective treatments, less toxicity, increased disease prevention, improved quality of life, and lower health care costs. Several endocrine-specific conditions are on the cusp of a breakthrough in diagnostic testing. The ability to test for specific genetic mutations that cause the syndrome of resistance to thyroid hormone can dramatically alter potential treatment options. Additionally, rare adrenal tumors called pheochromocytomas and paragangliomas are notoriously challenging to diagnose. Genetic tests can reduce delays in diagnosis, help determine whether a tumor is likely to be malignant, and provide doctors with critical data to help monitor family members who might also carry a problematic mutation[8].

Flat Funding Threatens Scientific Momentum

The Endocrine Society was encouraged by the $2 billion increase for NIH in the FY 2016 Omnibus Appropriations bill. This increase was desperately needed to allow the NIH to keep pace with inflation. 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.

The lack of sustained government support compounded by austerity measures such as sequestration has created an environment that is leading to a "brain drain," as gifted scientists

---

[5] Ken K. Y. Ho "Endocrinology: the next 60 years" *Journal of Endocrinology* (2006) 190, 3–6.

[6] Harrison Wein "Combination Therapy for Metastatic Prostate Cancer" *NIH Research Matters* August 24, 2015. http://www.nih.gov/news-events/nih-research-matters/combination-therapy-metastatic-prostate-cancer Accessed April 6, 2015.

[7] http://www.nih.gov/news-events/news-releases/hormone-treatment-restores-bone-density-young-women-menopause-condition Accessed April 6, 2015.

[8] Eric Seaborg, "Family History." *Endocrine News*, Feb. 2015. 15-17.

pursue other careers or leave the United States to develop important research breakthroughs and therapies elsewhere. In 2013, the number of NIH-supported scientists declined significantly, with nearly 1,000 NIH scientists dropping out of the workforce[9]. NIH scientists run labs that support high-quality jobs and education while generating breakthrough innovations. In 2011, the NIH directly or indirectly supported over 432,000 jobs across the country[10].

We may never be able to quantify the opportunities we have missed to improve the health and economic status of the United States due to persistent underinvestment in research. We do know however, that when "laboratories lose financing; they lose people, ideas, innovations and patient treatments[11]." Based on the personal stories of researchers who have been forced to curtail research programs, we know that research programs to understand how genetics can influence heart disease, develop therapeutic treatments for Parkinson's disease, and evaluate the effect of metal contaminants on reproductive health, among many others, are delayed or terminated[12].

FY 2017 NIH Funding Request

The Endocrine Society recommends that the Subcommittee provide at least $35 billion in funding for NIH in the FY 2017 Labor-HHS-Education Appropriations bill. This funding recommendation represents the minimum investment necessary to avoid further loss of promising research and at the same time allows the NIH's budget to keep pace with biomedical inflation.

It is critical that we continue to invest in biomedical research to improve the Nation's future financial situation. Rising healthcare costs threaten to consume an increasing percentage of the United States' GDP and also the individual budgets of workers and businesses[13]. The cost of diabetes, in particular, represents a staggering $245 billion in 2012 alone[14].

We live during an age of tremendous scientific opportunity that can only be realized through federal funding of biomedical research. Researchers are just beginning to harness the power of big data to solve complicated problems. Innovative new experiments and clinical research hold

[9] Jeremy Berg "The impact of the sequester: 1,000 fewer funded investigators." *ASBMB Today*. March (2014). https://www.asbmb.org/asbmbtoday/201403/PresidentsMessage/ Accessed March 20, 2014.
[10] Everett Ehrlich "Engine Stalled: Sequestration's Impact on NIH and the Biomedical Research Enterprise." *United for Medical Research*. (2012).
[11] Teresa K. Woodruff "Budget Woes and Research." *The New York Times*. September 10, 2013.
[12] Sequester Profiles: How Vast Budget Cuts to NIH are Plaguing U.S. Research Labs. *United for Medical Research*. http://www.unitedformedicalresearch.com/advocacy_reports/sequestration-profiles/ Accessed March 20, 2014.
[13] Dan Mangan "Job health insurance costs rising faster than wages." CNBC. 9 Dec. 2014. http://www.cnbc.com/id/102249938#. Accessed March 19, 2015.
[14] http://www.diabetes.org/advocacy/news-events/cost-of-diabetes.html Accessed March 19, 2015.

promise to solve some of the United States' greatest medical challenges and discover new ways to improve our quality of life. Government support is critical to these opportunities, and we encourage the Appropriations Committee to actively support promising and innovative research. We fully understand that the Appropriations Committee faces challenging decisions in FY 2017; however, we assert that additional cuts to the NIH and other non-defense discretionary programs is not the way to solve the budgetary issues facing the United States.

The Endocrine Society remains deeply concerned about the future of biomedical research in the United States without sustained support from the federal government. Flat funding levels would threaten the nation's scientific enterprise. The Society strongly supports increased federal funding for biomedical research in order to provide the additional resources needed to enable American scientists to address scientific opportunities and maintain the country's status as the preeminent research engine in the world. The Endocrine Society therefore asks that the NIH receive at least $35 billion in FY 2017.

AMERICAN ACADEMY OF
FAMILY PHYSICIANS
STRONG MEDICINE FOR AMERICA

Testimony to the House Subcommittee on Labor, Health and Human Services, & Education, and Related Agencies Appropriations FY 2017

April 15, 2016

The American Academy of Family Physicians (AAFP), which represents 120,900 family physicians and medical students across the country, submits this written statement for the record to urge the House Appropriations Committee to invest appropriately in our nation's primary care physician workforce in fiscal year 2017. In order to ensure high-quality, cost-effective health care for patients of all ages, the AAFP recommends that the Committee restore the discretionary budget authority for the Health Resources and Services Administration (HRSA) to the FY 2010 level of $7.48 billion and provide $364 million in budget authority for the Agency for Healthcare Research and Quality (AHRQ).

Within those agency budgets, we specifically highlight the need to provide the following appropriations for programs which are particularly important to family physicians and their patients:

- $59 million for Health Professions Primary Care Training and Enhancement authorized under Title VII, Section 747 of the *Public Health Service Act* ;
- An additional $70 million for the National Health Service Corps for a total program level of $380 million at least $20 million of which should be discretionary funding; and
- $364 million for the AHRQ to support research vital to primary care practice.

AAFP Headquarters
11400 Tomahawk Creek Pkwy.
Leawood, KS 66211-2680
800.274.2237 • 913.906.6000
fp@aafp.org

AAFP Washington Office
1133 Connecticut Avenue, NW, Ste. 1100
Washington, DC 20036-1011
202.232.9033 • Fax: 202.232.9044
capitol@aafp.org

HRSA – Title VII Primary Care Training & Enhancement

The Primary Care Training & Enhancement (PCTE) program administered by the Health Resources and Services Administration (HRSA) and authorized by Title VII, §747 of the *Public Health Service Act* of 1963 is important to support the education and training of family physicians. The PCTE strengthens medical education for physicians to improve the quantity, quality, distribution, and diversity of the primary care workforce. Without additional funding, there will be no new grant competitions for four more years. For that reason, we urge the Committee to increase the appropriation by $20 million from the FY 2016 level to $59 million in FY 2017.

An *Annals of Family Medicine* [http://www.annfammed.org/content/13/2/107.full] study projects that the rising number of primary care office visits for the expanding, aging, and increasingly insured population will require an additional 33,000 practicing primary care physicians by 2035. Another study in the same journal [http://www.annfammed.org/content/10/2/163] noted meeting the increased demand for primary care physicians would require a major investment in training. The article explicitly called for the expansion of Title VII, Section 747 to improve access to primary care. But we already face family physician shortages. A National Association of Community Health Centers report found that more than two-thirds of centers are actively recruiting for at least one family physician. [http://www.nachc.com/client/NACHC_Workforce_Report_2016.pdf]

The federal Advisory Committee on Training in Primary Care Medicine and Dentistry noted in a report released early in 2015 [http://www.hrsa.gov/advisorycommittees/bhpradvisory/actpcmd/Reports/eleventhreport.pdf] that the funds "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 system changes." The advisory committee recommended restoring funding to inflation-adjusted FY 2003 levels plus an additional $25 million per year over the next five years beginning in FY 2017 to permit annual competitive grant cycles for primary care training grants.

For decades, these grants to medical schools and residency programs have helped increase the number of physicians who select primary care specialties and who go on to work in underserved areas. A 2014 study of the effect of a PCTE grant addressing faculty development needs found that targeted federal funding can bring about changes that contribute to an up-to-date, responsive primary care workforce. [http://www.jgme.org/doi/full/10.4300/JGME-D-14-00329.1]

National Health Service Corps

Since in 1972, the National Health Service Corps (NHSC), also administered by HRSA, has offered financial assistance to recruit and retain health care providers to meet the workforce needs of communities across the nation designated as health professional shortage areas. The AAFP is committed to supporting the objectives of the NHSC in assisting communities in need of additional primary

care physicians, and we support the Administration's budget request for the NHSC of $20 million in discretionary appropriations for FY 2017.

The Government Accountability Office (GAO-01-1042T) described the NHSC as "one safety-net program that directly places primary care physicians and other health professionals in these medically needy areas." As the only medical society devoted solely to primary care, the AAFP recognizes the importance of the NHSC to the reducing geographic disparities in health care access.

Not only does the NHSC program of placing physicians and medical professionals in health professional shortage areas to meet the needs of patients in rural and medically underserved areas, it also provides scholarships as incentives for medical students to enter primary care and to provide health care to underserved Americans. By addressing medical school debt burdens, NHSC scholarships ensure wider access to medical education opportunities by providing financial support for tuition and other education expenses, and a monthly living stipend for medical students committed to providing primary care in underserved communities of greatest need.

More than 40,000 providers have served in the NHSC since its inception. In FY 2015, the National Health Service Corps (NHSC) had a field strength of 9,683 primary care and other clinicians. However, the need for primary care continues to exceed the available investment. The AAFP recommends that the Congress provide at least the program level of $380 million for the NHSC in FY 2017.

Agency for Healthcare Research and Quality – Primary Care Research

The Agency for Healthcare Research and Quality (AHRQ) is the sole federal agency charged with producing research to support clinical decision making, reduce costs, advance patient safety, decrease medical errors and improve health care quality and access. AHRQ provides the critical evidence reviews needed to answer questions on the common acute, chronic, and co-morbid conditions that family physicians encounter in their practices on a daily basis.

Without AHRQ research, too little is known about appropriate care for real patients in primary care practices. More attention and research need to be directed to patients with more than one mental or physical health condition. In 2000, for example, an estimated 60 million Americans had multiple chronic conditions. By 2020, that population is expected to grow to an estimated 81 million. Care for people with chronic conditions is expected to consume 80 percent of the resources of publicly funded health insurance programs by 2020. Treatment of patients with multiple chronic conditions already accounts for 51 percent of total health expenditures. Unfortunately, FY 2016 cuts harmed AHRQ's efforts to research the care of those with multiple chronic conditions. The agency's research initiative aimed at optimizing care for patients with multiple chronic conditions halted this year due to lack of funds. Restoring AHRQ's funding to FY 2015 levels will support research to provide primary care physicians the tools they need for evidence-based practice. The AAFP urges the Committee provide no less than $364 million in appropriated funds for AHRQ to support research vital to primary care.

RE: FY 2017 Appropriations for Department of Health and Human Services (HHS) Programs Impacting Americans with Alzheimer's Disease

As President and CEO of the Alzheimer's Foundation of America (AFA), a national nonprofit organization that unites more than 2,400 member organizations nationwide with the goal of providing optimal care and services to individuals confronting dementia, and to their caregivers and families I, Charles J. Fuschillo, Jr., urges the House Appropriations Committee to commit:

- **An additional $1 billion for Alzheimer's disease research at the National Institutes of Health (NIH); and**
- **An additional $40 million to fund caregiver supports and services provided by programs administered by the Administration for Community Living (ACL)**

National Institutes of Health (NIH):

AFA wants to commend the Committee for approving an historic increase in funding for Alzheimer's disease research at the National Institutes of Health (NIH) in FY'16. The $350 million in additional resources will help ensure promising research gets funded and that we move ever closer to the goal of finding a cure or disease-modifying treatment by 2025 as articulated in the National Plan to Address Alzheimer's Disease.

AFA hopes Congressional appropriators will continue to build upon this progress and make combatting Alzheimer's disease a national priority. To this end, **AFA urges the Committee to provide an additional $1 billion for Alzheimer's disease in FY'17.** Leading Alzheimer's disease scientists have called for $2 billion in annual research funding to keep us on track to achieve the 2025 goal. With just eight short years until the deadline, we can no longer wait. We need to ensure there is proper investment in promising research today that will get us to a cure tomorrow. An increase of $1 billion in FY'17 would put research funding close to that $2 billion dollar target.

AFA also urges the Committee to include $34.5 billion in total funding for NIH, as recommended by the Ad Hoc Group for Medical Research. Even if funding remains flat, NIH's actual budget will still be effectively cut as spending will not be able to keep pace with biomedical inflation.

Administration on Community Living (ACL) programs:

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

- National Family Caregiver Support Program (NFCSP): NFCSP provides grants to states and territories, based on their share of the population aged 70 and over, to fund a range of supportive services that assist family and informal caregivers in caring for their loved ones at home for as long as possible, thus providing a more person-friendly and cost-effective approach than institutional care. Last year's appropriation of $150.5 million cannot possibly keep up with the need for care as our population ages. **AFA urges that $161 million be appropriated in FY'17 to support this important program.**

- Lifespan Respite Care Program (LRCP): **AFA urges the Committee to commit $9 million, a $4 million increase to LRCP in FY'17.** LRCP provides competitive grants to state agencies working with Aging and Disability Resource Centers and non-profit state respite coalitions and organizations to make quality respite care available and accessible to family caregivers regardless of age or disability.

- The Alzheimer's Disease Supportive Services Program (ADSSP) provides competitive grants to states to expand dementia-capable home and community-based long-term services and supports. It was funded at $4.8 million in FY'16. **AFA is calling for an increase of $2.5 million to bring the ADSSP up to $7.3 million** in FY '17.

- Alzheimer's Disease Initiative (ADI): **AFA supports a budget request of $16.5 million—a $6 million increase for this program**—in FY'17 that provides grants for services such as supporting caregivers in the community, improving health care provider training, and raising public awareness. Research shows that education, counseling and other support for family caregivers can delay institutionalization of loved ones and improve a caregiver's own physical and mental well-being—thus reducing costs to families and government. In addition, AFA supports an **appropriation of $6.7 million, a $2.5 million increase, for the Alzheimer's Disease Communications Campaign.**

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

FY 2017 Written Testimony in support of the Corporation for National and Community Service
Submitted by Tom Branen, Senior Advisor, America's Service Commissions

On behalf of America's Service Commissions (ASC), the national association of the 52 state and territorial service commissions, I offer this written testimony in support of FY 2017 funding for the Corporation for National and Community Service (CNCS) and its programs. In summary, ASC writes in support of CNCS' budget in several key areas of importance to state service commissions: State Service Commission Support Grants ($17 million), Community Program Development, Innovation and Capacity Building Funds ($7.5 million), AmeriCorps State and National ($386 million), and Volunteer Generation Fund ($10 million).

When Congress created CNCS in 1993, it envisioned national service as a shared federal-state partnership, providing a central role for governors in designing and implementing national service through governor-supported state service commissions (commissions). Commissions perform vital functions and are invaluable partners to CNCS. More than 1,000 private citizens serve as governor-appointed commissioners, leading and guiding national service efforts in their states by identifying local needs, directing federal and state resources, ensuring oversight and accountability, tracking performance measures and community impact, and leading citizen service efforts in their states and territories. State service commissions develop, administer, and support more than $250 million in AmeriCorps funding in their states. State service commissions determine the compelling needs in their state, set policy and program priorities, competitively award grants to local

nonprofits and agencies, provide training and technical assistance, monitor grantees to ensure quality and compliance with federal and state law, and broadly promote service and volunteering in their states.

Commissions are a vital resource that help governors tap the power of citizens to solve problems and strengthen communities. Commissions provide the most efficient low cost delivery system for national and community service. Commissions leverage the federal investment in national and community service by matching most investments dollar for dollar. State service commissions provide the critical infrastructure needed to ensure that national and community service reaches across the nation to small faith- and community-based nonprofits that are addressing critical local needs.

State Commissions Support Grants build the capacity of state service infrastructure. This funding is critical to ensure appropriate oversight and effective performance monitoring. State Commission Support Grants are matched dollar for dollar and are allocated according to a population-based formula. State Commission Support Grants demonstrate the important state-federal partnership and are a model of devolution. In FY 2017 we recommend $17 million for State Commission Support Grants. As commissions are responsible for more than $250 million in federal program funds, we believe $17 million is a reasonable request to ensure high-quality, effective programming and oversight.

Community Program Development, Innovation and Capacity Building Funds

Additionally, we recommend $7.5 million in continued support of Community Program Development, Innovation and Capacity Building Funds (i.e., Training and Technical

Assistance Commission Investment Fund) via the Subtitle J provision in statute. Implementing high quality, impactful, and effective service programs is the goal of state commissions and is best achieved when they have sufficient resources and tools. Small investments in development and support of new programs result in large payoffs when underserved communities are able to access national service programming.

The Oklahoma Community Service Commission is a nonprofit state commission whose primary purposes are to integrate, expand and sustain volunteer service initiatives across the state of Oklahoma as well as fund and administer AmeriCorps programs in Oklahoma. When faced with challenges such as illiteracy, poverty, crime and environmental problems, our nation has always relied on the dedication and action of citizens. In Oklahoma, the Oklahoma Community Service Commission matches federal and local resources and volunteers with nonprofit agencies, schools and community groups. The result is afterschool tutoring and mentoring programs for at-risk youth, and other programs that improve lives, meet critical needs and help create a positive future.

State Service Commission Administered Programs:

- **AmeriCorps State** – AmeriCorps State grants provide financial support to public and nonprofit organizations that sponsor service programs around the country to recruit, train and place AmeriCorps members to meet critical community needs in education, health, economic opportunity, veterans affairs, disaster services, and the environment. State service commissions determine the needs of their state and competitively award AmeriCorps State grants to local nonprofits and agencies

within their state. We support the President's FY 2017 budget request of $386 million for AmeriCorps State and National.

In Ardmore, Oklahoma, the **Cities in Schools AmeriCorps** program provides one-on-one and small group literacy instruction for pre-K-5th grade for at-risk youth in an afterschool and a summer program. The students who finished the afterschool program were on grade level in reading and in math. The summer program helped students maintain or increase their level of reading and math skills.

- **Volunteer Generation Fund** – The Volunteer Generation Fund (VGF) strengthens the nation's civic infrastructure by helping nonprofits recruit, manage, and support additional volunteers. The VGF grants support commissions to identify effective approaches to increase the number of volunteers, strengthen the capacity of volunteer connector organizations to recruit and retain volunteers, and develop strategies to effectively use volunteers to solve local problems. In FY 2017 we recommend $10 million for the Volunteer Generation Fund.

The **CaliforniaVolunteers Service Enterprise Initiative**, developed via VGF support, is a train-the-trainer model to increase the effectiveness and impact of nonprofit organizations through the strategic engagement of volunteers. Over three years of the VGF grant, volunteer centers in California have worked with 234 nonprofits to complete the service enterprise training. More than 85 percent of these organizations indicated in post-surveys that they are more effectively engaging competency/skills-based volunteers, resulting in improved internal

operational and financial systems to enhance organizational sustainability. In partnership with CaliforniaVolunteers, Points of Light, and others, nonprofits around the country are now accessing training to become certified as service enterprises. This effort will change the way in which organizations view and engage volunteers to support their organizational missions.

Thank you for the opportunity to share this testimony and the important work of state commissions and the Corporation for National and Community Service.

WRITTEN TESTIMONY FOR THE RECORD FROM
DR. IVY TURNBULL, DEPUTY EXECUTIVE DIRECTOR
AIDS ALLIANCE FOR WOMEN, INFANTS, CHILDREN, YOUTH & FAMILIES
TO THE SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES, EDUCATION, AND RELATED AGENCIES
HOUSE COMMITTEE ON APPROPRIATIONS
APRIL 15, 2016

Dear Chairman Cole and Members of the Subcommittee:

AIDS Alliance for Women, Infants, Children, Youth & Families was founded in 1994 to help respond to the unique concerns of HIV-positive and at-risk women, infants, children, youth, and families. AIDS Alliance conducts policy research, education, and advocacy on a broad range of HIV/AIDS prevention, care, and research issues. We are pleased to offer written testimony for the record in opposition of the FY 2017 budget proposal consolidating Ryan White Part D funding into Part C and in support of maintaining Part D of the Ryan White Program as part of the FY 2017 Labor, Health and Human Services, Education, and Related Agencies appropriations measure. This testimony also has the support of the Elizabeth Glaser Pediatric AIDS Foundation.

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 Ryan White Part D Programs, providing $75,008, 000 million to the program in FY 2016, restoring dedicated funding eliminated in the President's FY 2016 budget proposal. While the AIDS Alliance for Women, Infants, Children, Youth & Families understands that these are difficult economic times, we are requesting the Subcommittee to maintain its commitment to the Ryan White Part D program and again restore its dedicated funding eliminated in the President's FY 2017 budget proposal and increase Ryan White Part D funding by $9.9 million in FY 2017.

Ryan White Part D Background and History

Over concerns with the increase in the number of pediatric AIDS cases, Congress first acted to address pediatric cases in 1987 by providing $5 million for the Pediatric AIDS Demonstration Projects in the FY 1988 budget. Those demonstration projects became part of the Ryan White CARE Act of 1990 and today are known as Ryan White Part D and have served approximately 200,000 women, infants, children, youth and family members. Since the program's inception in 1988, Part D programs have been and continue to be the entry point into medical care for women and youth. The family-centered primary medical and supportive services provided by Part D are uniquely tailored to address the needs of women, including HIV positive pregnant women, HIV exposed infants, children and youth. Part D programs are the only perinatal clinical service available to serve HIV-positive pregnant women and HIV exposed infants, when payments for such services are unavailable from other sources. Ryan White Part D programs have been extremely effective in bringing the most vulnerable populations into and retained in care and is the lifeline for women, infants, children and youth living with HIV/AIDS. The Part D programs

continue to be instrumental in preventing mother-to-child transmission of HIV and for ensuring that women, including HIV- positive pregnant women, HIV exposed infants, children and youth have access to quality HIV care. The program is built on a foundation of combining medical care and essential support services that are coordinated, comprehensive, and culturally and linguistically competent. This model of care addresses the health care needs of the most vulnerable populations living with HIV/AIDS in order to achieve optimal health outcomes.

In 2012, Part D provided funding to 114 community-based organizations, academic medical centers and hospitals, federally qualified health centers, and health departments in 39 states and Puerto Rico. These grantees also provide support services which include case management (medical, non-medical, and family-centered); referrals for inpatient hospital services; treatment for substance use, and mental health services. Part D grantees 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 two decades.

A Response to Women, Infants, Children, and Youth

While accounting for less than 5 percent of Ryan White direct care dollars (minus ADAP and Part F), Ryan White Part D programs have been extremely effective in bringing our most vulnerable populations into care and developing medical care and support services especially designed to reach women, children, youth, and families. Part D funded programs played a leading role in reducing mother-to-child transmission of HIV-from more than 2,000 newborn

infections annually more than a decade ago to an estimated 174 in 2014 through aggressive efforts to reach out to pregnant women. Appropriate funding is critical to maintain and improve upon this success, as there are still approximately 8,500 HIV-positive women giving birth every year in the U. S. that need counseling, services and support to prevent pediatric HIV infections. According to the CDC, youth aged 13-24 accounted for more than 1 in 5 new HIV diagnoses in the US in 2014. Most new HIV infections in youth (about 55 percent) occur in young Black gay and bisexual males. Of the new HIV infections among youth, 80 percent are among young women of color. Ryan White Part D programs are the entry point into medical care for many of these HIV- positive youth as this is the age group least likely to have access to quality healthcare. According to the Health Resources and Services Administration, more than 37 percent of women receiving medical care in Ryan White Programs. Additionally, 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. Full implementation of the Affordable Care Act (ACA), along with continuation of the Ryan White Program will dramatically improve health access and outcomes for many more women, infants, children, and youth living with HIV disease.

Proposed Consolidation

The medical and supportive services provided by Ryan White Part D are uniquely tailored to address the needs of women, including HIV positive pregnant women, HIV exposed infants, children and youth living with HIV/AIDS and are not currently being provided by other parts of the Ryan White Program, including Ryan White Part C. The proposed consolidation of Part D

funding into Part C in the federal budget would eliminate a strong safety net for our most vulnerable populations. Furthermore, the loss of Part D funds in some community areas would profoundly impact access to comprehensive HIV care and treatment for women, infants, children and youth. Many of the population served by Part D will be lost or never enter into care thus increasing the existing gaps in the HIV Care Continuum. Moreover, major program changes that are this controversial should be left to Congress and should not be done through the appropriations process.

Conclusion

While we recognize the need to reduce administrative burdens associated with the overall operational aspects of Ryan White programs , the elimination of dedicated funding for Ryan White Part D in FY 2017, and the proposed Part C/D consolidation would undoubtedly destabilize existing models of care created to address the unique needs of our most vulnerable populations with HIV and jeopardizes the success of retaining these populations in life-saving HIV care and treatment ensuring achieved and maintained viral load suppression. We again urge the Committee to reject the President's FY 2017 budget proposal to eliminate dedicated funding for Ryan White Part D and move the funding to Part C, and respectfully request that the Committee include language in the appropriations bill attesting to such. Without the Ryan White Part D program, many of these medically-underserved women, infants, children and youth would not receive the vital primary care and support services provided to them for the last two decades. We sincerely thank you for all that you do to ensure that women, infants, children, and youth, living with HIV receive the much needed care and treatment services required to sustains their lives.

Drew Perschon's story, as submitted by his mom- Kate Perschon

On November 6, 2007, following more than a month of mysterious eye "injury", misinterpreted by opthamologists, our then 22 month old son, Drew, was diagnosed with stage IV neuroblastoma. Cancer. In my baby. There was nothing else that could have shocked us more. How did our baby get cancer? What did he eat? What was in our water? What could we have done to prevent it? The answer was nothing. There was nothing we could have done.

There is no feeling more sickening, more heart-wrenching than knowing your child had a very high likelihood of dying in your arms, before your eyes. Having no control, other than the desperate prayers in your heart, the blessing of insurance and the Godsend of modern medicine to take a stab at the monster that had ravaged his little body. Inside this boy, this marvelous boy, were thirteen tumors, the largest 9 centimeters in diameter, resting like a sleeping bear on top of his kidney. His blood and bone marrow were packed up with these horrific cells. His eye was bulging out from the tumor behind it, pushing his eye out of its socket. The eye "injury" mystery had been solved, and there was nothing more treacherous it could have been.

New words, new faces, new life we lived. I was eight months pregnant with our second child. As he started chemo, sick from the flu on top of it, I couldn't hold him for more than a few minutes at a time. Doctors warned me that the poison sitting in his filled diaper could pass through my own pores into my unborn child. I couldn't change him or clean up after the daily hurricane that accompanies chemotherapy and influenza. Our families -what would we have done without them- moved in and out of our home like ghosts, trying to help us maintain any semblance of normalcy as we drove back and forth in the hour long journey to downtown Chicago and the then Children's Memorial Hospital.

It was a long time, or it seemed like a long time, before we knew if anything was working. We lost our dog (also to cancer), we had a baby, I left my job. As drugs delivered by security teams were pumped into my toddler's body, we wondered, "Is it saving him? Is it killing him?" Each day we weren't in treatment felt as wrong as the days we were treating. "What's that cancer doing now? Right now, today, while he watches Barney and drinks from his sippy cup? Is it growing? Is it taking him from us?" My heart was outside of myself.

And then. Then somehow he became the miracle. He responded. We thought perhaps he would maybe make it to the 30% of the children diagnosed with stage IV neuroblastoma that survived five years. Five years seemed light years away, but our grandest, most coveted prize.

The list was long, the journey longer, the wait and heartache and exhaustion the longest. It read with numbers dotted like the lines of a twisted Christmas song: Five rounds of chemotherapy. Three surgeries. Two stem cell harvests. Three stem-cell transplants. Twenty rounds of radiation. 10 rounds of maintenance chemo. And one boy. One boy finally, sweetly, miraculously in remission.

It was all we ever wanted. It's still all we ever want.

We brought him home on his half-birthday from the last transplant- July 11 he was two and a half. The local fire and police departments brought in a welcome home parade and escorted our old Subaru to the driveway. He stepped out of the car and reached down to touch the grass in our yard, as if he had thought before that he might never be home again. Instead he was home for good. We were never admitted overnight at the hospital again.

Eight years have passed. Our Drew is 10 years old. He's an honor student. A baseball fanatic. A book worm. A science nut. A friend. A brother. A son. A hero. And now it's about living. Living because he was given the chance to live. And it's not enough to just live and move on. It's wonderful, don't mistake me! Life is wonderful just for the having. But we know that's not what life is about. Life is about living despite what's happened to you and BECAUSE of what's happened to you. Life is about making your pain into hope. We wouldn't be doing it right if we just lived and moved on without taking this story and making it bigger than us.

When people hear Drew's story, we call him our miracle. Drew's story is rare. We grabbed the prize- the coveted prize that every parent begs and prays for when a child has cancer. Survival.

But it's a prestigious prize, indeed. Saved for a select few with no criteria for success that our human brains can comprehend. It isn't about money. It isn't about faith. It isn't about hard work or love or sheer will. It's rare, and there's no way to win the prize on your own merit.

Why is it a rare, coveted prize? Why do only a few of us get to take our children home when it's all said and done? Why do you have so many other stories in this stack of a child who was? It doesn't have to be so. Turn the tables. Help. Help our kids so that everyone gets to take home the prize. Even better, help them never have to fight for it in the first place.

Thank you for your time. Thank you for your service to our country. Thank you for loving our kids.

WESTERN RESERVE ILC

4076 Youngstown Road SE
Suite 203
Warren, Ohio, 44484

Phone: 330-372-3325
Fax: 330-373-1826

Pam Davies

Executive Director

Western Reserve Independent Living Center

I am writing to support the National Council on Independent Living's request for Congress to reaffirm your commitment to the more than 57 million Americans with disabilities by increasing funding in the HHS appropriations for Centers for Independent Living (CILs). I am asking that you increase funding by $200 million, for a total of $301 million for the Independent Living line item in FY 2017.

CILs are cross-disability, non-residential, community-based, nonprofit organizations that are designed and operated by individuals with disabilities. CILs are unique in that they are directly governed and staffed by people with all types of disabilities, including people with mental, physical, sensory, cognitive, and developmental disabilities. Each of the 365 federally funded centers provides five core services: information and referral, individual and systems advocacy, peer support, independent living skills training, and transition services, which were added with the passage of the Workforce Innovation and Opportunity Act (WIOA). From 2012-2014, CILs have provided the core services to nearly 5 million people with disabilities, and provided additional services such as housing assistance, transportation, personal care attendants, and employment services to hundreds of thousands of individuals. During this same period, prior to transition being added as a core service, CILs transitioned 13,030 people with disabilities from nursing homes and other institutions into the community with cost savings to the federally funded long-term care programs. These cost savings are a wise investment of public dollars.

Transition services were added as a fifth core service with the 2014 reauthorization of the Rehabilitation Act within the Workforce Innovation and Opportunity Act. Transition services include the transition of individuals with significant disabilities from nursing homes and other institutions to home and community-based residences with appropriate supports and services, assistance to individuals with significant disabilities at risk of entering institutions to remain in the community, and the transition of youth with significant disabilities to postsecondary life. This core service is vital to achieving full participation for people with disabilities.

Every day, CILs are fighting to ensure that people with disabilities gain and maintain control over their own lives. We know that this cannot occur when people reside in institutional settings. Opponents of deinstitutionalization say that allowing people with disabilities to live in the community will result in harm. We know that the 13,030 people with disabilities who CILs successfully transitioned out of nursing homes and institutions from 2012-2014 prove otherwise. Additionally, when services are delivered in an individual's home, the result is a tremendous cost

WESTERN RESERVE ILC

4076 Youngstown Road SE
Suite 203
Warren, Ohio, 44484

Phone: 330-372-3325
Fax: 330-373-1826

savings to Medicaid, Medicare, and states. Community-based services enable people with disabilities to become less reliant on long-term government supports, and they are significantly less expensive than nursing home placements. We are grateful that Congress demonstrated their understanding and support for community-based services when WIOA was passed and transition was added as a fifth core service.

Since transition services were added as a core service, the need for funding is critical. Moreover, CILs need additional funding to restore the devastating cuts to the Independent Living program, make up for inflation costs, and address the increased demand for independent living services. In 2016, the Independent Living Program is receiving $2.5 million less in funding than it was in 2010. It is simply not possible to meet the increasing demand for services and effectively provide transition services without additional funding. Increased funding should be reinvested from the billions currently spent to keep people with disabilities in costly Medicaid nursing homes and institutions and out of mainstream society.

Centers for Independent Living play a crucial role in the lives of people with disabilities, and work tirelessly to ensure that people with disabilities have a real choice in where and how they live, work, and participate in the community. Additionally, CILs are an excellent service and a bargain for America, keeping people engaged with their communities and saving taxpayer money. NCIL is dedicated to increasing the availability of the invaluable and extremely cost-effective services CILs provide, and they have submitted written testimony with a similar request. I strongly support NCIL's testimony.

There are some CILS in the US that operate without federal funding. These centers could potentially close from being underfunded. Besides the five core services, CILS work in and with the community to promote full access and inclusion. The closing of any of these centers defeats the goal of state wideness in providing services to people with disabilities in our country. As one of the Part B only funded centers, for eight years we have struggled with not being able to provide all the services our area needs. We have new programs that we have developed that need the funding backup to initiate and other programs we are currently developing. Being a consumer controlled agency, we constantly survey our consumers as to their needs. A few areas of need that our consumers have expressed are everyday transportation, home modifications, assistive technology, medical equipment, recreational opportunities, youth transitioning, and educational supports. Thank you for the opportunity to provide testimony.

STATEMENT OF THE NATIONAL KIDNEY FOUNDATION
30 EAST 33RD STREET NEW YORK, NY 10016

SUBMITTED TO THE HOUSE COMMITTEE ON APPROPRIATIONS; SUBCOMMITTEE ON LABOR, HHS, EDUCATION, AND RELATED AGENCIES

April 15, 2016

The National Kidney Foundation (NKF) is America's largest and oldest health organization dedicated to the awareness, prevention and treatment of kidney disease for hundreds of thousands of healthcare professionals, millions of patients and their families, and tens of millions of people at risk. NKF works with volunteers to offer the scientific, clinical and kidney patient perspective on what needs to be done to prevent kidney disease, delay progression, and better treat kidney disease and kidney failure. In addition, NKF has provided evidence-based clinical practice guidelines for all stages of chronic kidney disease (CKD), including transplantation since 1997 through the NKF Kidney Disease Outcomes Quality Initiative (NKF KDOQI). NKF has local division and affiliate offices serving our constituents in all 50 states.

NKF is pleased to submit testimony regarding the impact of Chronic Kidney Disease (CKD), and steps that can be taken by Congress to build upon the success of the existing programs at the National Institutes of Health, Centers for Disease Control, and Health Resources and Services Administration to improve early detection and treatment of the disease.

About CKD

Chronic Kidney Disease (CKD) is a condition characterized by a gradual loss of kidney function over time. CKD impacts 26 million American adults, while 1 in 3 (73 million) American adults are at risk for kidney disease. Diabetes and high blood pressure are responsible for up to two-thirds of all cases of irreversible kidney failure (end stage renal disease). Kidney disease can be detected through a simple urine test, yet the disease can go undetected until very advanced because kidney disease often has no symptoms. When kidney disease progresses, it may lead to kidney failure, which requires dialysis or a kidney transplant to maintain life. Rates of kidney failure are higher among minorities, with African Americans developing ESRD at a rate of 3 to 1 compared to Whites and Hispanic Americans developing it at a rate of 2 to 1.

The Importance of Early Detection of CKD

Only 10% of individuals with CKD are aware they have it.[1] CKD is often asymptomatic -- especially in the early stages -- and therefore goes undetected without laboratory testing. Some people are not diagnosed until they have reached end-stage renal disease (ESRD) and must begin dialysis immediately.

At the end of 2014, 661,648 Americans had End Stage Renal Disease (ESRD), including 468,386 dialysis patients and 193,262 kidney transplant recipients. Complicating the cost and human toll is the fact that it is a disease multiplier, with patients very likely to be diagnosed with

[1] Tuot DS, Plantinga LC, Hsu CY, et al. Chronic kidney disease awareness among individuals with clinical markers of kidney dysfunction. Clin J Am Soc Nephrol. Aug 2011;6(8):1838-1844.

cardiovascular disease. ESRD was present in less than 2% of Medicare beneficiaries but responsible for nearly 6% of Medicare expenditures.

Cost-effective early identification and treatment options exist which can slow the progression of kidney disease, delay complications, and prevent or delay kidney failure. Intervention at the earliest stage is vital to improving outcomes, lowering health care costs, and improving patient experience, yet in a recent clinical study only 12% of primary care clinicians were properly detecting CKD in their patients with diabetes who are at the highest risk of kidney disease.[2] There often is a misconception that once someone is diagnosed with CKD, there must be a referral to a nephrologist. However, it is not necessary in most instances for referral to a nephrologist in early stages.

The CKD Intercept Initiative

NKF is moving forward on an initiative we announced two years ago to help improve early detection and diagnosis of CKD by primary care practitioners (PCP). Our CKD Intercept initiative aims to transform PCP detection and care of the growing numbers of Americans with CKD by deploying evidence based clinical guidelines into primary care settings through education programs, symposia and practical implementation tools.

In support of this effort, NKF is advocating for Congress to enact legislation to remove the reimbursement barriers to earlier, better CKD care management by directing the Secretary of Health and Human Services to create a Medicare bundled payment demonstration for CKD management to primary care practitioners and nephrologists. Given the high costs and comorbidities associated with late diagnosis of CKD, this demonstration is expected to improve patient outcomes, lower hospitalizations and result in savings to Medicare. NKF commissioned a study to develop a cost estimate model on improving earlier detection and management of CKD. Through early intervention, Medicare could reduce spending by $4.8 billion in year 10 and $8.2 billion in year 20, for a total reduction in spending of $93 billion over 20 years.

While progression of CKD can lead to ESRD, CKD patients are at a greater risk of death, cardiovascular events and adverse drug events. In a most recent study conducted by The Johns Hopkins University, testing for kidney disease – in those with the disease – may be a stronger risk predictor of heart attack and stroke than tobacco use, blood pressure, or high cholesterol.[3] . Testing for kidney disease in at-risk populations provides the opportunity for interventions to foster awareness, foster adherence to medications and control risk factors. Therefore, NKF's initiatives address three priorities in the *National Strategy for Quality Improvement in Health Care*, including 1) making care safer by reducing harm caused in the delivery of care, 2) promoting the most effective prevention and treatment of the leading causes of mortality, starting with cardiovascular disease, and 3) working with communities to promote widespread use of best practices to enable healthy living.

---

[2] Szczech LA, et al. Primary Care Detection of Chronic Kidney Disease in Adults with Type-2 Diabetes: The ADD-CKD Study (Awareness, Detection and Drug Therapy in Type 2 Diabetes and Chronic Kidney Disease), PLOS One November 26, 2014.

[3] Matsushita, Kunihiro, Estimated glomerular filtration rate and albuminuria for prediction of cardiovascular outcomes: a collaborative meta-analysis of individual participant data, Lancet Diabetes Endocrinol. Published online May 29, 2015, http://dx.doi.org/10.1016/S2213-8587(15)00040-6.

With the continued support of Congress, NKF is confident a feasible detection, surveillance and treatment program can be advanced to as a *first step* to slow the progression of kidney disease. These initiatives will help build on the CDC's investment in the Chronic Kidney Disease Program.

CDC Chronic Kidney Disease Program

NKF urges the Committee to provide $2.31 million for the CKD program for FY 2017, an increase of $200,000. Prior to the creation of the Chronic Kidney Disease Program at CDC in FY 2006, no national public health program focusing on early detection and treatment of CKD existed. The CDC CKD program has consisted of three projects to promote kidney health by identifying and controlling risk factors, raising awareness, and promoting early diagnosis and improved outcomes and quality of life for those living with CKD. These projects include (1) demonstrating approaches for identifying individuals at high risk for CKD through state-based screening; (2) conducting an economic analysis on the economic burden of CKD and the cost-effectiveness of interventions; and (3) establishing a surveillance system for CKD by analyzing and interpreting information to assist in prevention and health promotion efforts for kidney disease. The surveillance project includes a CDC website program containing information on risk factors, early diagnosis, and strategies to improve outcomes.

As a result of consistent congressional support, the National Center for Chronic Disease Prevention and Health Promotion at CDC has instituted a series of projects that could assist in attaining the Healthy People 2020 objectives. However, increasing the proportion of persons with CKD who know they are affected requires acquiring additional data sources beyond Medicare claims and NHANES survey analyses to identify the undiagnosed population and assess the burden of CKD across the country to better understand the CKD impact at a state and local level. This momentum will be stifled and CDC's investment in CKD to date jeopardized if line-item funding is not increased.

A study published by researchers leading the program shows that the burden of kidney disease is increasing and that over half of U.S. adults age 30-64 are likely to develop CKD.[4] Congressional support for an increase in funding to the CDC program will benefit kidney patients and those at risk for kidney disease, advance the objectives of Healthy People 2020 and the National Strategy for Quality Improvement in Health Care, and fulfill the mandate created by Sec. 152 of the Medicare Improvement for Patients and Providers Act. Agency priorities going forward include assessing disparities among racial and socioeconomic populations and adding new and local data on CKD including additional risk factors.

NIDDK

NKF supports the Friends of NIDDK request of $2.16 billion for the Institute in FY 2017. Medicare spent $99 billion in 2014 caring for patients with kidney disease, $68 billion of which was for individuals who do not have kidney failure, yet NIH funding for kidney disease research is only about $600 million annually. Many research proposals with the potential to lead to

[4] Hoeger, Thomas, et al. The Future Burden of CKD in the United States: A Simulation Model for the CDC CKD Initiative, Am J Kidney Dis. 2015;65(3):403-411.

improved treatments, including reconstructing the kidney to restore function, remain unfunded. Patients deserve better and we cannot allow these opportunities to slip away.

In March, NKF hosted the Third Annual Kidney Patient Summit that included participation from nearly 100 advocates from NKF and four other kidney patient organizations. Increased federal support for kidney disease research was a top priority in meetings with the advocates' congressional delegations. This is particularly important for individuals whose kidney disease is the result of genetic factors. America's scientists are at the cusp of many potential breakthroughs in improving our understanding of CKD and providing new therapies to delay and treat various kidney diseases. With the unique status of ESRD in the Medicare program, CKD research has the potential to provide cost savings to the federal government like that of no other chronic disease. We urge Congress to again provide strong bipartisan support for NIH to continue building on the success of the FY 16 efforts, and fund NIDDK at this requested level.

HRSA Organ Transplantation

NKF urges the Committee to provide $28.5 million for organ donation and transplantation programs in the HRSA DoT. This request is broadly supported by patient and professional members of the transplant community to restore the program's purchasing power to the FY 2010 level. Activities supported by DoT include initiatives to increase the number of donor organs, and the National Donor Assistance Program which helps individuals obtain a transplant by assisting living organ donors with expenses such as travel and subsistence that are not reimbursed by insurance, a health benefit program, or any other state or federal program.

As of April 8, 2016, the kidney transplant wait list consisted of 100,269 individuals plus an additional 1,927 waiting for a combined kidney / pancreas donation. Transplantation remains the treatment of choice for most patients with kidney failure yet few will be given this opportunity. Kidney recipients often have an improved quality of life (and are more likely to stay in or return to the work force) and transplantation is tremendously cost effective -- Medicare spends $29,920 per year on a kidney recipient after the year of transplant, compared to more than $84,450 annually on a dialysis patient.

In 2014, NKF established an organ donation task force to review the state of organ donation and identify opportunities to expand the number of transplants. While the task force continues to develop its recommendations, some activities are being implemented, one example of which is NKF's "The Big Ask/The Big Give" campaign. This initiative, currently in the pilot phase, promotes and supports awareness of living kidney donation. It is designed for both those waiting for a kidney transplant who have trouble asking somebody to consider donation (The Big Ask) and potential kidney donors (The Big Give). The Big Ask/The Big Give provides the necessary education and platform to take the misconceptions and confusion out of what can be a very complex process. We intend to offer the program nationwide in transplant centers, dialysis centers and nephrology practices.

Thank you for your consideration of our funding requests for Fiscal Year 2017.

Testimony Submitted by the American Congress of Obstetricians and Gynecologists (ACOG)
Submitted by: Rebecca Nathanson, Federal Affairs Manager
To the U.S. House Committee on Appropriations
Subcommittee on Labor, Health and Human Services, Education, and Related Agencies
Department of Health and Human Services (HHS)

The American Congress of Obstetricians and Gynecologists, representing more than 57,000 physicians and partners in women's health, is pleased to offer this statement to the Senate Committee on Appropriations, Subcommittee on Labor, Health and Human Services, Education, and Related Agencies. We thank Chairman Cole, Ranking Member DeLauro, and the entire Subcommittee for this opportunity to provide comments on some of the most important programs to women's health.

Today, the U.S. lags behind many other nations in healthy births. ACOG believes that federal research investments, including comprehensive data collection and surveillance, biomedical research, and translating research into evidence-based care for women and babies is necessary to improve maternal and infant health. We urge you to make funding of the following programs and agencies a top priority in FY17.

Data Collection and Surveillance at the Centers for Disease Control and Prevention (CDC):

In order to conduct robust research, it is critical to collect uniform, accurate and comprehensive data. The National Center for Health Statistics is the nation's principal health statistics agency and collects raw vital statistics from state records like birth and death certificates. This information provides key data about both mother and baby during pregnancy, labor, and delivery. Effective data collection depends on all states having adequate resources to expand technical assistance to maximize electronic death reporting by funeral directors and physicians. In addition, states must be able to modernize their systems to keep pace with new technology. ACOG requests funding to be used to support states in upgrading antiquated systems and improving the quality and accuracy of vital statistics reporting. **For FY17, ACOG requests $170 million for the National Center for Health Statistics.**

The Pregnancy Risk Assessment Monitoring System (PRAMS) at CDC extends beyond vital statistics and surveys new mothers on their experiences and attitudes during pregnancy, with questions on a range of topics, including what their insurance covered, whether they had stressful experiences during pregnancy, when they initiated prenatal care, and what kinds of questions their doctor covered during prenatal care visits. By identifying trends and patterns in maternal health, CDC researchers and state health departments are better able to identify behaviors and environmental and health conditions that may lead to preterm births. Only 40 states use the PRAMS surveillance system today. **ACOG requests adequate funding to expand PRAMS to all U.S. states and territories.**

Biomedical Research at the National Institutes of Health (NIH):

Biomedical research is critically important to understanding the causes of maternal and infant mortality and morbidity and developing effective interventions to lower the incidence of mortality and morbidity. The Eunice Kennedy Shriver National Institute of Child Health and Human Development's (NICHD's) 2012 Scientific Vision identified the most promising research

opportunities for the next decade. Goals include determining the complex causes of prematurity and developing evidence-based measures for its prevention within the next ten years, understanding the long term health implications of assisted reproductive technology, and understanding the role of the placenta in fetal health outcomes. The placenta, one of the least studied human organs, is essential to the viability and proper growth of the fetus. NICHD's Human Placenta Project will help discover the causes of placental failures, and ultimately ways to prevent failure and improve maternal and fetal birth outcomes.

In addition, adequate levels of research require a robust research workforce. The years of training combined with uncertainty in receiving grant funding are major disincentives for students considering a career in this field. This has resulted in a huge gap between low number of women's reproductive health researchers being trained and the immense need for research. We urge continued investments in the Women's Reproductive Health Research (WRHR) Career Development program, Reproductive Scientist Development Program (RSDP), and the Building Interdisciplinary Research Careers in Women's Health (BIRCWH) programs to address the shortfall of women's reproductive health researchers. **ACOG supports a minimum of $34.5 billion for NIH and $1.441 billion within that funding request for NICHD in FY17.**

Public Health Programs at the Health Resources and Services Administration (HRSA) and the Centers for Disease Control and Prevention (CDC):

Projects at HRSA and CDC serve the essential purpose of translating research into evidence-based practice. Where NIH conducts research to identify causes of maternal and infant mortality and morbidity, CDC and HRSA help ensure those research findings lead to improved maternal and infant health outcomes.

Maternal and Child Health Block Grant (HRSA): The Maternal and Child Health Block Grant at HRSA is the only federal program that exclusively focuses on improving the health of mothers and children. State and territorial health agencies and their partners use MCH Block Grant funds to reduce infant mortality, deliver services to children and youth with special health care needs, support comprehensive prenatal and postpartum care, screen newborns for genetic and hereditary health conditions, deliver childhood immunizations, and prevent childhood injuries.

These early health care services help keep women and children healthy, eliminating the need for later costly care. Every $1 spent on preconception care for a woman with diabetes can save up to $5.19 by preventing costly complications. Even so, block grant funding has been significantly diminished. Over $90 million has been cut from the Block Grant since 2003. **ACOG requests $880 million for the Block Grant in FY17 to maintain its current level of services.**

Title X Family Planning Program (HRSA): Family planning and interconception care are imperative to ensuring healthy women and healthy pregnancies. The Title X Family Planning Program provides essential services to more than 4.5 million low income men and women who may not otherwise have access to these services. Title X clinics accounting for $5.3 billion in health care savings in 2010 alone. For every $1 spent on publicly funded family planning services, Medicaid and other public expenditures saved $7.09. **ACOG supports $327 million for Title X in FY17 to sustain its level of services.**

Fetal Infant Mortality Review (HRSA): HRSA's Healthy Start Program promotes community-based programs to reduce infant mortality and racial disparities. These programs are encouraged to use the Fetal and Infant Mortality Review (FIMR), which brings together ob-gyn experts, local health departments, consumers and community stakeholders to address local issues contributing to infant mortality. Today, more than 172 local programs in over 30 states find FIMR a powerful tool to help reduce infant mortality and address issues related to preterm delivery. ACOG has partnered with the Maternal and Child Health Bureau to sponsor the National FIMR Program for over 25 years. **ACOG supports $0.5 million in FY17 for HRSA to increase the number of Healthy Start programs that use FIMR.**

Maternal Health Initiative (HRSA): The Maternal and Child Health Bureau launched the Maternal Health Initiative to foster the notion of "healthy moms make healthy babies." As part of this effort, ACOG has convened the National Partnership on Maternal Safety to identify key factors to reduce maternal morbidity and mortality. **For FY17, ACOG requests, at a minimum, level funding for MCHB to advance this important work.**

Safe Motherhood, Maternity and Perinatal Quality Collaboratives (CDC): The Safe Motherhood Initiative at CDC works with state health departments to collect information on pregnancy-related deaths, track preterm births, and improve maternal outcomes. Through Safe Motherhood, CDC funds state-based Maternity and Perinatal Quality Collaboratives that improve birth outcomes by encouraging use of evidence-based care, including reducing early elective deliveries. For instance, through the Ohio Perinatal Quality Collaborative, started in 2007 with funding from CDC, 21 OB teams in 25 hospitals have significantly decreased early non-medically necessary deliveries, in accordance with ACOG guidelines, reducing costly and dangerous pre-term births. Avalere Health estimated that reducing early elective deliveries can save from $2.4 million to $9 million per year. Currently, there are active Perinatal Quality Collaboratives in many states, like Maryland and Washington, that have demonstrated significant progress in reducing early elective deliveries, among other quality improvement initiatives. They do so without federal funds, and face major financial stability challenges. Many states do not yet have collaboratives, and could benefit greatly using active, successful, and well-funded collaboratives as a model to build a collaborative tailored to unique and local needs. The PREEMIE Reauthorization Act, enacted in 2013, authorizes funding to increase the number of states receiving assistance for Perinatal Quality Collaboratives. **ACOG urges you to reinstate the pre-term birth sub-line at a funding level of $2 million, as authorized by PREEMIE, and fund the Safe Motherhood Initiative at $46 million to implement PREEMIE and help states expand or establish Maternity and Perinatal Quality Collaboratives.**

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

Each year, more than 4 million women give birth in the United States and more than 3 million breastfeed their infants. However, little is known about the effects of most drugs on the woman and her child, or the ways in which pregnancy and lactation alter the uptake, metabolism, and effect of medication. Pregnant and breastfeeding women have historically been excluded from most research trials. Although there have been substantial encouraging developments in this arena,

including the recently updated drug labeling rule on pregnancy and lactation by FDA and relevant research at NIH and CDC, significant gaps remain. In order to achieve meaningful progress, HHS must ensure the coordination of all efforts being made at the agency level. **As such, ACOG supports the establishment of a federal work group to improve coordination and provide guidance on how clinical research might be done appropriately in this area.**

Quality Assessment Programs at the Agency for Healthcare Research and Quality (AHRQ):

Consumer Assessment of Healthcare Providers and Systems (CAHPS): The Consumer Assessment of Healthcare Providers and Systems (CAHPS) program was established within AHRQ in 1995 to address concerns regarding the lack of available consumer health plan reviews. The information collected through the CAHPS program can be a critical element of patient decision-making, while also informing providers and insurers about the impact and reception of their initiatives and services. Unfortunately, the CAHPS program has not yet established a survey to collect data about maternity care. Given the frequency and complex nature of interactions that an expectant mother will have with an effective healthcare system, we support the creation of a CAHPS survey focused on maternity care. **ACOG encourages the CAHPS program to direct funds towards the development of a maternity care-oriented assessment.**

Again, we would like to thank the Committee for its commitment to improving women's health, and we urge you to fund the programs we have identified in FY17.

U.S. Government Response to Zika Virus:

In order to continue to adequately respond to and better understand the Zika virus' origins, transmission, and public health risks, particularly to pregnant women, ACOG urges Congress to fund a robust and comprehensive public health response to the rapid spread of the Zika virus.

ACOG applauds the Administration's recent steps to bolster U.S. capacity to combat Zika by previously committed federal funds, but additional funding is desperately needed. **ACOG urges Congress to prioritize emergency supplemental funding to combat Zika and replenish funds that have been transferred by the Administration.** The health of women and infants is central to ACOG's mission, and we believe that these funding measures are essential to ensure execution of a comprehensive Zika response.

Infectious Diseases Society of America

Testimony of the Infectious Diseases Society of America (IDSA)
on the Fiscal Year 2017 Department of Health and Human Services Budget
Prepared for the U.S. House of Representatives
Subcommittee on Labor-HHS-Education Appropriations
Submitted by Johan S. Bakken, MD, PhD, FIDSA, IDSA President
April 15, 2016

On behalf of the Infectious Diseases Society of America (IDSA), I offer testimony in support of the U.S. Department of Health and Human Services (HHS) agencies and programs that contribute to the prevention, detection and treatment of infectious diseases (ID). IDSA represents more than 10,000 physicians and scientists dedicated to promoting health through excellence in ID research, education, prevention, and patient care. IDSA urges the Subcommittee to provide necessary Fiscal Year (FY) 2017 funding for public health and biomedical research activities that ultimately save lives, contain health care costs and promote economic growth. More specifically, **IDSA encourages the Subcommittee to provide $7.8 billion for the Centers for Disease Control and Prevention (CDC) and $34.5 billion for the National Institutes of Health (NIH). IDSA also asks that the Subcommittee act swiftly to provide the $1.9 billion requested by the administration to prevent and respond to the Zika virus.**

Our community of infectious diseases professionals is particularly concerned by the growing public health crisis of antimicrobial resistance (AR). We witness firsthand the impact that AR has on individuals. As a result, we have aggressively advocated for the creation and implementation of a comprehensive federal response. IDSA applauds Congress, and in particular the many champions on this Subcommittee, for appropriating approximately $380 million in new funding during the FY 2016 cycle to begin implementation of the *National Action Plan for Combating Antibiotic-Resistant Bacteria* (Action Plan). The Action Plan details and coordinates prevention, surveillance, antibiotic stewardship, as wells as research and development (R&D) activities across federal agencies –as recommended by the President's Council of Advisors on Science and Technology (PCAST) in their September 2014 *Report to the President on Combating Antibiotic Resistance*.

We know that the federal response to antimicrobial resistance must be sustained in order to stem the tide that already results in over two million infections and 23,000 deaths each year. In March 2016, the Presidential Advisory Council on Combating Antibiotic-Resistant Bacteria (PACCARB) released a draft of its *Initial Assessments of the National Action Plan for Combating Antibiotic-Resistant Bacteria*. The report states that "Combating AMR [antimicrobial resistance] requires an adequate resource base to slow down, control, and hopefully reverse the problem. Simply stated, the USG [U.S. Government] must commit sufficient resources to solving the problem with funding continued over a long period of time." The president's budget for FY 2017 requests the resources necessary to continue implementation of the Action Plan. **IDSA urges the Subcommittee to provide the funding increase requested for the CDC Antibiotic Resistance Solutions Initiative. We ask that the final FY 2017 Labor-HHS-Education Appropriations bill also support the Action Plan activities carried out by the NIH, Biomedical Advanced Research and Development Authority (BARDA) and the Agency for Healthcare Research and Quality (AHRQ).**

Infectious Diseases Society of America

The Zika virus is another serious public health threat that is of considerable interest to our members. We are witnessing the first widespread transmission of the Zika virus in the Americas. While the mosquito-borne virus generally causes mild illness or no symptoms, it has been linked to birth defects in infants born to mothers who were infected during pregnancy. The federal government now has a window of opportunity to help contain the Zika virus in Zika-endemic countries, as well as to enhance state/ local prevention and response efforts, increase epidemiology and surveillance capacity, and support R&D for vaccines, diagnostics and therapeutics. **We ask that Congress immediately fund the president's request to combat the Zika virus. As a temporary measure, the Administration recently repurposed $600 million to address the Zika Virus. However, these funds will need to be replaced and are insufficient to provide the necessary response.**

CENTERS FOR DISEASE CONTROL AND PREVENTION

National Center for Emerging and Zoonotic Infectious Diseases (NCEZID)

The NCEZID leads CDC efforts to address antibiotic resistance as well as helps confront emerging public health threats such as the Zika virus.

We ask that NCEZID be provided the $629.5 million requested by the Obama administration, including $200 million for continuation of the Antibiotic Resistance Solutions Initiative, which was initiated with FY 2016 support from this Subcommittee. The requested FY 2017 funding would allow CDC to expand FY 2016 Healthcare-Associated Infections (HAI)/AR prevention efforts from 25 states to up to 50 states, six large cities, and Puerto Rico. CDC plans to award the majority of the FY 2017 increased AR funding to states. The CDC projects that over five years the initiative will lead to a 60% decline in health-care associated carbapenem-resistant Enterobacteriaceae (CRE), 50% reduction in *Clostridium difficile*, 50% decline in bloodstream methicillin-resistant *Staphylococcus aureus* (MRSA), 35% decline in health-care associated multidrug-resistant *Pseudomonas* spp., and 25% reduction in multidrug-resistant *Salmonella* infections, eclipsing the costs of the program.

IDSA also supports the proposed budget of $21 million for the National Healthcare Safety Network (NHSN) to increase the number of participating healthcare facilities from 19,000 to as many as 20,000 by the end of FY 2017, as well as to increase the number of sites reporting antibiotic use data from 130 in 30 states to 750 in all 50 states. Information provided to the NHSN is critical for evaluating the success of interventions designed to reduce inappropriate antibiotic use and limit the development of resistance.

IDSA recommends that at least $30 million be allocated for the Advanced Molecular Detection (AMD) initiative in FY 2017. This funding will allow CDC to more rapidly determine where emerging diseases come from, whether microbes are resistant to antibiotics, and how microbes are moving through a population. During the 2014/2015 Ebola outbreak, AMD methods were utilized to determine whether the virus was changing as it spread through different populations, which facilitated appropriate responses.

Infectious Diseases Society of America

Global Health Security

IDSA supports CDC continued efforts to implement the Global Health Security Agenda, which would accelerate the efforts of the U.S. and partner nations to prevent, detect and slow the spread of infectious diseases across borders. We ask that you provide the Global Health Security initiative with at least the funding requested in the FY 2017 PBR.

IDSA also encourages the Subcommittee to increase research, monitoring, and evaluation efforts for malaria and neglected tropical diseases. Zika and Chikungunya infections, as well as Chagas disease and dengue fever have been reported in the United States. At least 40% of the world's population is at risk for serious illness and death from mosquito-borne viral diseases.

CDC plays a central role in responding to new outbreaks such as of Ebola virus disease in 2014/2015 and Zika virus infections in 2015/2016. The spread of Zika virus through South America, Central America, the Caribbean and now into the U.S. is the latest example of the fact that infectious diseases respect no national borders and that the CDC must be appropriately funded to maintain readiness to be ahead of new crises. The requested funding will build response and prevention in the U.S. and territories as well as international surveillance and public health capacity. The request expands the Field Epidemiology Training Program, laboratory testing, healthcare provider training, and surveillance and control in countries at highest risk for an outbreak. The requested resources will also accelerate R&D for medical countermeasures, including vaccines and diagnostics.

IDSA also urges the Subcommittee to include $132 million for the CDC Global AIDS Program, which plays a unique role in building sustainability by funding physicians, epidemiologists, and public health advisors in countries hit hardest by the AIDS epidemic.

National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention (NCHHSTP)

Despite a misperception as a disease of the past, tuberculosis now causes more deaths than any other single infectious disease agent, with 9.6 million new illnesses and 1.5 million deaths in 2014. Approximately 480,000 of those cases were caused by multidrug-resistant (MDR) tuberculosis, including 9.7% that were extensively drug-resistant (XDR). In December, 2015, the Obama administration released the *National Action Plan to Combat Multi-Drug Resistant (MDR) Tuberculosis*, a comprehensive plan to address drug-resistant TB in the U.S. and abroad and accelerate MDR-TB R&D. **In order to fund the plan and put the U.S. back on the path towards TB elimination, IDSA recommends a budget of $243 million in FY2017 for the CDC Division of Tuberculosis Elimination.**

IDSA recommends an increase of $30 million for NCHHSTP to enhance the response to the viral hepatitis epidemic that has been fueled by injection drug use associated with opioid addiction. Sustained funding of at least $157.3 million is also necessary for HIV and STD prevention and surveillance activities.

National Center for Immunization and Respiratory Diseases

Immunizations are among the most cost-effective clinical preventive services. However, national adult immunization rates remain low for most routinely recommended vaccines. Each year in the U.S., tens of thousands of adults die from illnesses that are preventable through

vaccination. Additionally, vaccine-preventable diseases and related complications result in billions of dollars annually in direct and indirect healthcare costs. IDSA asks that the CDC Immunization Grant Program (Section 317) be funded at least at the FY 2016 level of $611 million.

IDSA recommends that the Subcommittee provide at least the $188 million proposed in the PBR for CDC efforts to control influenza. CDC plays a critical role in seasonal and pandemic influenza preparedness and response, including conducting surveillance activities that inform response efforts and providing public communications regarding influenza prevention and treatment.

NATIONAL INSTITUTES OF HEALTH

National Institute of Allergy and Infectious Diseases (NIAID)

Within NIH, NIAID should be funded at least at $4.716 billion as requested in the FY 2017 PBR. Further, we believe that NIAID should be provided an increase that is proportionate to any increase provided to the NIH as a whole. The NIAID plays a leading role in research for new rapid ID diagnostics, vaccines and therapeutics. The January 2015 IDSA report, *Better Tests, Better Care: The Promise of Next Generation Diagnostics* explains that advances in biomedical research over the last few decades have created the potential for increasingly simple, fast and reliable diagnostic tests for infectious diseases. By allowing physicians to quickly distinguish between bacterial and viral infections, better diagnostics can lead to faster and more appropriate treatments for patients, help preserve the utility of our existing drugs, and aid in identifying individuals to participate in clinical trials. Last year, NIAID awarded more than $11 million in first-year funding for research to develop diagnostics to rapidly detect antibiotic-resistant bacteria. NIAID also recently announced awards of approximately $5 million for non-traditional alternatives to antibiotics. These efforts as well as research on new antimicrobials and vaccines are set to ramp up with the $100 million increase made last year. We ask that the Subcommittee continue this work in FY 2017.

The Antibacterial Resistance Leadership Group (ARLG), led by researchers at Duke University and the University of California San Francisco, is an example of extramural research to address AR made possible by NIAID. The ARLG manages a clinical research agenda to increase knowledge of antibacterial resistance. The ARLG has supported early clinical research on new antibacterials as well as on diagnostics that rapidly identify resistant bacteria. Continued operation of the ARLG depends on support from the NIAID.

Office of AIDS Research

Federal investments in HIV/AIDS research have led to much longer lives for those living in countries where treatment is available. Continued investment in HIV/AIDS research through NIH is critically important. We urge the Subcommittee to provide at least $3.45 billion for the Office of AIDS Research (OAR). The level-funding of HIV/AIDS research since 2015 threatens work towards a vaccine as well as discourages individuals from entering the field.

Infectious Diseases Society of America

ASSISTANT SECRETARY FOR PREPAREDNESS AND RESPONSE (ASPR)
Biomedical Advanced Research and Development Authority

BARDA is a critical initiator of public-private collaborations for antibiotic, diagnostic and vaccine R&D. PCAST has identified BARDA as best positioned to elicit private investments necessary to address antibiotic resistance. IDSA recommends that the Subcommittee provide $607 million for BARDA in FY 2017. Such funding is necessary to allow BARDA to pursue additional work on antibiotic development while maintaining its strong focus on other medical countermeasures to address biothreats.

We also request that in any final version of FY 2017 appropriations language, you strongly urge BARDA to include TB in their new and emerging infectious disease efforts and invest in the development of new TB diagnostics, drugs and vaccines as part of the CARB initiative and the Emerging Infectious Diseases program at BARDA.

CENTER FOR MEDICARE AND MEDICAID SERVICES

Despite the significant and vital contributions ID physicians make to patient care, research and public health, their work continues to be undervalued. Over 90% of the care provided by ID physicians is considered evaluation and management (E&M). Current E&M codes fail to reflect the increasing complexity of E&M work. ID physicians often care for patients with chronic illnesses, including HIV, hepatitis C, and recurrent infections. Such care involves preventing complications and exploring complicated diagnostic and therapeutic pathways. ID physicians also conduct significant post-visit work, such as care coordination, patient counseling and other necessary follow up.

New research is needed to better identify and quantify the inputs that accurately capture the elements of complex medical decision-making. Such studies should take into account the evolving health care delivery models with growing reliance on team-based care, and should consider patient risk-adjustment as a component to determining complexity. Research activities should include the direct involvement of physicians who primarily provide cognitive care. **We urge the Subcommittee to include report language in the FY 2017 funding bill asking that "CMS undertake research necessary to develop new E&M codes and accompanying documentation requirements that more precisely describe the cognitive work in these physician-patient encounters, and that the results of such research be made publicly available no later than two years after the passage of this Act."**

AGENCY FOR HEALTHCARE RESEARCH AND QUALITY

IDSA supports the $12 million requested in the president's budget for FY 2017 for research to develop improved methods and approaches for combating antibiotic resistance and conducting antibiotic stewardship activities in multiple healthcare settings, with a focus on long-term and ambulatory care settings.

Once again, thank you for the opportunity to submit this statement on behalf of the nation's ID physicians and scientists. We rely on strong federal partnerships to keep Americans healthy and urge you to support these efforts. Please forward any questions to Jonathan Nurse at jnurse@idsociety.org or (703) 299-0202.

Written Testimony of the Emergency Nurses Association (ENA)
Fiscal Year 2017 Appropriations
House Appropriations Subcommittee on Labor, Health and Human Services, Education, and Related Agencies
Submitted by 2015 ENA President Kathleen E. Carlson, MSN, RN, CEN, FAEN
April 14, 2016

The Emergency Nurses Association (ENA), with more than 41,000 members worldwide, is the only professional nursing association dedicated to defining the future of emergency nursing and emergency care through advocacy, expertise, innovation, and leadership. My name is Kathleen Carlson, the 2016 President of ENA. Founded in 1970, ENA develops and disseminates education and practice standards and guidelines, and affords consultation to both private and public entities regarding emergency nurses and their practice. ENA has a great interest in the work of the Senate Labor, Health and Human Services, Education Subcommittee and especially its efforts to improve the quality of emergency care for patients in the United States. For fiscal year 2017, ENA respectfully requests $28 million for Trauma and Emergency Care Programs (HHS; ASPR), $244 million for Nursing Workforce Development programs (HHS; HRSA), $20.213 million for the Emergency Medical Services for Children program (HHS; HRSA), $22.846 million to fund poison control centers (HHS; HRSA) and $157 million for the National Institute of Nursing Research (HHS; NIH).

Trauma and Emergency Care Programs

Trauma is the leading cause of death for persons younger than 44 and the fourth-leading cause of death for all ages. In states with an established trauma system, patients are 20 percent more likely to survive a traumatic injury. Further, victims of traumatic injury treated at a Level I trauma center are 25% more likely to survive than those treated at a general hospital.

Our trauma and emergency medical systems are designed to transport seriously injured individuals to trauma centers quickly. However, due to a lack of financial resources, 45 million

Americans do not have access to a major trauma center within the "golden hour" following an injury when chances of survival are highest.

Trauma and emergency care programs, which are authorized under the Public Health Service Act, provide much-needed money to the states to develop and enhance of trauma systems. These programs are critical to the efficient delivery of services through trauma centers, as well as to the development of regionalized systems of trauma and emergency care that ensure timely access for injured patients to appropriate facilities. This modest investment can yield substantial returns in terms of cost efficiencies and, most importantly, saved lives.

Therefore, ENA respectfully requests $28 million in FY 2017 for trauma and emergency care programs.

Nursing Workforce Development Programs

The nursing profession faces significant challenges to ensure that there will be an adequate number of qualified nurses to meet the growing healthcare needs of Americans. A growing elderly population will seek healthcare services in a multitude of settings and the care they depend upon will require a highly educated and skilled nursing workforce. In addition, demand for nurses will grow because of the increased emphasis on preventative care and the growing number of Americans with health insurance. A 2014 projection from the U.S. Bureau of Labor Statistics' *2014 Occupational Outlook Handbook* anticipates that the number of practicing RNs will grow 26 percent by 2020 and the employment of Advanced Practice Registered Nurses will grow even more rapidly.

At the same time, the aging of the Baby Boom generation will deplete the nursing ranks as well. During the next 10 to 15 years, approximately one-third of the current nurse workforce will reach retirement age. The retirement of these experienced nurses has the potential to create a serious deficit in the nursing pipeline. At the same time, our colleges cannot keep up with the demand for new nurses. According to a 2013-2014 survey by the American Association of

Colleges of Nursing, 78,089 qualified applications were turned away from nursing schools in 2013 alone.

Title VIII Nursing Workforce Development programs address these factors and help support the training of qualified nurses. They not only enhance nursing education at all levels, from entry-level to graduate study, but they also support nursing schools that educate nurses for practice in rural and medically underserved communities. Another important part of Title VIII is the Faculty Loan Program which is critical to alleviating the large shortage in nursing faculty. Overall, more than 65,000 nurses and nursing students were trained and educated last year with the help of Title VIII nursing workforce development programs.

Therefore, ENA respectfully requests $244 million in FY 2017 for the Nursing Workforce Development programs authorized under Title VIII of the Public Health Service Act.

Emergency Medical Services for Children

The Emergency Medical Services for Children (EMSC) program is the only federal program that focuses specifically on improving the pediatric components of the emergency medical services (EMS) system. EMSC aims to ensure state-of-the-art emergency medical care for ill and injured children or adolescents; that pediatric services are well integrated into an EMS system backed by optimal resources; and that the entire spectrum of emergency services is provided to children and adolescents no matter where they live, attend school, or travel.

The federal investment in the EMSC program produces a wide array of benefits to children's health through EMSC State Partnership Grants, EMSC Targeted Issue Grants, the Pediatric Emergency Care Applied Research Network, and the National EMSC Data Analysis Resource Center.

Therefore, ENA respectfully requests $20.213 million in FY 2017 for the EMSC program.

Poison Control Centers

Poisoning is the second most common form of unintentional death in the United States. In 2009, 31,768 deaths nationwide were attributed to unintentional poisoning. Children are especially vulnerable to injury by poisoning and each day 300 children are treated for poisoning in emergency departments across the country and two die.

The nation's 55 poison control centers handle 3.4 million calls each year, including approximately 680,000 calls from nurses and doctors who rely on poison centers for an immediate assessment and expert advice on poisoning cases.

Not only are America's network of poison centers invaluable for treating victims of poisonings, but the work of the centers also results in substantial savings to our healthcare system. About 90 percent of people who call with poison emergencies are treated at home and do not have to visit an emergency department. In more severe poisoning cases, the expertise provided by poison control centers can decrease the length of hospital stays. It has been estimated that every dollar spent on America's poison control centers saves $13.39 in health care costs and lost productivity. The positive impact to the federal budget is also significant. A 2012 study by the Lewin Group found that poison control centers resulted in $313.5 million in savings to Medicare and $390.2 million in savings to Medicaid.

Therefore, ENA respectfully requests $22.846 million in FY 2017 for poison control centers.

The National Institute of Nursing Research (NINR)

As one of the 27 Institutes and Centers at the NIH, NINR funds research that lays the groundwork for evidence-based nursing practice. NINR's mission is to promote and improve the health of individuals, families, communities, and populations. The Institute supports and conducts clinical and basic research on health and illness to build the scientific foundation for

clinical practice, prevent disease and disability, manage and eliminate symptoms caused by illness, and improve palliative and end-of-life care.

NINR nurse-scientists examine ways to improve care models to deliver safe, high-quality, and cost-effective health services to the nation. Our country must look toward prevention as a way of reducing healthcare expenditures and improving outcomes. The work of NINR is an important part of this effort.

Moreover, NINR helps to provide needed faculty to support the education of future generations of nurses. Training programs at NINR develop future nurse-researchers, many of whom also serve as faculty in our nation's nursing schools.

Therefore, ENA respectfully requests $157 million in FY 2017 for the NINR.

Written Testimony for the Record
American Society of Anesthesiologists (ASA)
FY 2017 Appropriations for the National Institutes of Health
Subcommittee on Labor, Health and Human Services, Education and Related Agencies
Committee on Appropriations
United States House of Representatives
April 15, 2016

The American Society of Anesthesiologists (ASA) is an educational, research, and scientific association of physicians organized to raise and maintain the standards of anesthesiology and improve the care of the patient. Since its founding in 1905, the Society's achievements have made it an important voice in medicine and the foremost advocate for all patients who require anesthesia or relief from pain.

Physician anesthesiologists are responsible for preparing the patient for surgery, administering anesthesia to relieve pain, and for managing vital life functions. After surgery, they maintain the patient in a comfortable state during the recovery and are involved in the provision of critical care medicine in the intensive care unit. Physician anesthesiologists are experts at managing post-operative pain, and they may also treat patients with chronic pain outside of the acute care setting.

ASA respectfully submits this testimony on the need for federal investment in anesthesia and pain medicine research supported by the National Institutes of Health (NIH). ASA supports research on the impact of anesthesia on two vulnerable populations: pediatric and senior patients. ASA also supports research on acute and chronic pain management and the rational and safe use of opioids, including basic and clinical research on the biopsychosocial mechanisms that produce and maintain chronic pain and the development of innovative non-opioid pain therapies.

The safety of drugs used for anesthesia and sedation in children - There is concern that anesthetics and sedatives may cause long-term abnormalities in behavior, learning, and memory when administered to infants and toddlers. Concerns about the safety of anesthetic drugs for infants and young children initially arose when scientific studies in young animals showed that commonly used anesthetics can be harmful to the developing brain and result in adverse effects on behavior, learning, and memory. Accumulating evidence from studies in children suggests a similar association between surgery with anesthesia in early childhood and subsequent cognitive and behavioral abnormalities. Experts agree that additional preclinical and clinical research efforts are necessary; this research will help determine if particular anesthetics are hazardous to young children, to design the safest anesthetic regimens, to develop practice guidelines, and to potentially foster the development of new anesthetic drugs.

On November 19, 2014 the Food and Drug Administration (FDA) Science Board held a meeting to review existing data related to the use and potential toxicity of anesthetics in the pediatric population. ASA and the Society for Pediatric Anesthesia submitted a letter to the FDA Science Board noting the "relative dearth of reports studying the neurodevelopmental effect of anesthetics in humans," but that "even a modest effect, if real, could have profound public health consequences given the millions of anesthetics that are provided to children around the world

each year." The FDA Science Board's overall consensus was that there is a high likelihood that the troubling animal findings are translatable to humans.

The FDA also joined SmartTots, a Public-Private Partnership that coordinates and funds research with the goal of making anesthesia safer for the pediatric population. In November 2015, SmartTots, with ASA, the American Academy of Pediatrics, and other health professional societies, issued a Consensus Statement on the Use of Anesthetic and Sedative Drugs in Infants and Toddlers which states:

> "Concern has been raised about the safety of the medicines used for anesthesia and sedation in young children. This concern is based on research in animals demonstrating long-term, possibly permanent, injury to the developing brain caused by exposure to these medicines. This injury results in abnormalities in behavior, learning, and memory in animals. The effect of exposure to anesthetic drugs in young children is unknown; however, some but not all studies have suggested that problems similar to those seen in animals could also occur in infants and toddlers. It is important to recognize that the studies in children suggest that similar deficits may occur. These studies in children have limitations that prevent experts from understanding whether the harmful effects were due to the anesthetic drugs or to other factors such as the surgery or related illness. Better research is required to understand whether children are harmed and if so, what alternative medicines might be used to minimize risk from anesthesia. Because there is not enough information about the effects of anesthetic drugs on the brains of young children, it is not yet possible to know whether use of these medicines poses a risk, and if so, whether the risk is large enough to outweigh the benefit of the planned surgery, procedure, or test."

Anesthesia and sedation in senior citizens- In senior citizens, post-operative delirium and post-operative cognitive dysfunction are commonplace and are associated with increased post-operative morbidity and mortality. According to "Controversies in anesthesia for noncardiac surgery in older adults" in the *British Journal of Medicine*, while the importance of delirium to the immediate postoperative course is largely recognized, the longterm outcomes of postoperative delirium remain to be described in high-quality studies.[1]

Postoperative delirium is a common consequence of anesthesia in the elderly, which can lead to longer hospital stays, poor recovery, and higher death rates. As the country's population ages, identifying patients at high-risk for developing postoperative delirium is increasingly important. According to the US Census, the population age 65 yr and older is expected to more than double between 2014 and 2060, increasing from 47.8 million (14.8% of the total population) to 98.1 million (23.6%). The US National Hospital Discharge Survey showed that in 2010, patients age 65 yr and older constituted 33% of hospital discharges and 44% of days of inpatient care. Moreover, the amount of surgery performed in older patients is increasing at a rate greater than

---

[1] Murthy S, Hepner DL, Cooper Z, Bader AM, Neuman MD. Controversies in anaesthesia for noncardiac surgery in older adults. *Br J Anaesth*. 2015 Dec;115 Suppl 2:ii15-ii25. doi: 10.1093/bja/aev396.

the aging of the population. As such, the care of older surgical patients is of increasing importance.[2]

The incidence of postoperative delirium ranges from two to 33 percent in elderly patients undergoing major surgery, depending on the patient's risk factors and the degree of operative stress. Patients who have postoperative delirium can suffer from fluctuating inattention, disorientation, lethargy, agitation, and combative behavior. By better understanding who may be at higher risk of post-operative delirium, physician anesthesiologists can develop interventions, such as considering giving patients antipsychotic medications before surgery, carefully monitoring the depth of anesthesia, and/or having patients see a geriatrics specialist prior to surgery.

Postoperative cognitive dysfunction (POCD) is a distinct phenomenon from postoperative delirium, but like postoperative delirium it disproportionately affects the elderly. Given that age is a strong predictor of POCD, the rate is expected to grow as the population ages. POCD is the deterioration of cognition after surgery that may last from a few days to weeks. POCD can take the form of memory loss and cognitive impairment, and is associated with longer hospital stays and an altered quality of life.

Chronic pain and the rational and safe use of opioids- There is a dual crisis of chronic pain and opioid misuse, abuse, and diversion in the United States. Pain is the most common complaint for which patients seek medical attention. According to the Institute of Medicine, approximately 100 million U.S. adults have common chronic pain conditions at an annual cost of $560-635 billion.[3] In addition, the number of prescriptions for opioids has risen dramatically, and their greater availability has been accompanied by an alarming increase in opioid overdose deaths. The treatment of acute and post-surgical pain with opiates has increasingly become a gateway to chronic opioid use and addiction. In 2014 alone, more than 28,000 people died from opioid overdoses.[4] To relieve the burden of chronic pain and to reduce opioid overdose fatalities, ASA believes it is a health care safety and quality imperative to expand investment into basic and clinical research on the biopsychosocial mechanisms that produce and maintain chronic pain, to develop innovative non-opioid therapies to treat acute and chronic pain, to develop improved treatments for acute pain that minimize the use of opioids, and to foster a greater understanding by physicians and the public on the rational and safe use of opioids.

The American Society of Anesthesiologists is committed to quality of care and patient safety. In 2016, ASA will launch a patient safety initiative on improving brain health, fostering understanding, developing best practices, and increasing awareness of postoperative cognitive dysfunction and delirium with the goal of laying the groundwork for research into minimizing its effects. We look forward to continuing to work with Congress in order to address the need for

---

[2] Ibid.

[3] (2011). Relieving Pain in America: A Blueprint for Transforming Prevention, Care, Education, and Research. Washington, DC, Institute of Medicine.

[4] Centers for Disease Control and Prevention. (2016). Injury Prevention and Control: Opioid Overdose. Retrieved from http://www.cdc.gov/drugoverdose/ on 11 April, 2016.

research on the impact of anesthesia on vulnerable populations and on acute and chronic pain management and the safe use of opioids.

4-13-16

From: Mel Clarrage

To: Subcommittee on Labor, Health and Human Services, and Education, and Related Agencies

Re: Centers for Independent Living (CILs)

My name is Mel Clarrage, Chair of the Maine Statewide Independent Living Council (SILC). I am writing on behalf of the Maine SILC to support the National Council on Independent Living's request for Congress to reaffirm your commitment to the more than 57 million Americans with disabilities by increasing funding in the HHS appropriations for Centers for Independent Living (CILs). I am asking that you increase funding by $200 million, for a total of $301 million for the Independent Living line item in FY 2017.

CILs are cross-disability, non-residential, community-based, nonprofit organizations that are designed and operated by individuals with disabilities. CILs are unique in that they are directly governed and staffed by people with all types of disabilities, including people with mental, physical, sensory, cognitive, and developmental disabilities. Each of the 365 federally funded centers provides five core services: information and referral, individual and systems advocacy, peer support, independent living skills training, and transition services, which were added with the passage of the Workforce Innovation and Opportunity Act (WIOA). From 2012 - 2014, CILs provided the core services to nearly 5 million people with disabilities, and provided additional services such as housing assistance, transportation, personal care attendants, and employment services to hundreds of thousands of individuals. During this same period, prior to transition

being added as a core service, CILs transitioned 13,030 people with disabilities from nursing homes and other institutions into the community. As Maine moves forward as the first cross-disability Employment First state in the nation, the Maine SILC is acutely aware of the need for adequate funding to sustain relevant independent living services that support full community inclusion.

Transition services were added as a fifth core service of CILS with the 2014 reauthorization of the Rehabilitation Act within WIOA. Transition services include the transition of individuals with significant disabilities from nursing homes and other institutions to home and community-based residences with appropriate supports and services, assistance to individuals with significant disabilities at risk of entering institutions to remain in the community, and the transition of youth with significant disabilities to postsecondary life. This core service is vital to achieving full participation for people with disabilities.

Every day, CILs are fighting to ensure that people with disabilities gain and maintain control over our own lives. We know that this cannot occur when people reside in institutional settings. Opponents of deinstitutionalization say that allowing people with disabilities to live in the community will result in harm. We know that the 13,030 people with disabilities who CILs successfully transitioned out of nursing homes and institutions from 2012 - 2014 prove otherwise. Additionally, when services are delivered in an individual's home, the result is a tremendous cost savings to Medicaid, Medicare, and states. Community-based services enable people with disabilities to become less reliant on long-term government supports, and they are significantly less expensive than nursing home placements. We are grateful that Congress

demonstrated their understanding and support for community-based services when WIOA was passed and transition was added as a fifth core service.

Since transition services were added as a core service, the need for funding is critical. Moreover, CILs need additional funding to restore the devastating cuts to the Independent Living program, make up for inflation costs, and address the increased demand for independent living services. In 2016, the Independent Living Program is receiving $2.5 million less in funding than it was in 2010. It is simply not possible to meet the increasing demand for services and effectively provide transition services without additional funding. Particularly with the full implementation of both WIOA and the Medicare Settings Rule, it would be unjustifiable for individuals with disabilities to remain in institutions, or be at risk to enter them, due to insufficient funds to support independent living. Likewise, lack of funding for appropriate services should not dictate the options available for community living. Increased funding should be reinvested from the billions currently spent to keep people with disabilities in costly Medicaid nursing homes and institutions and out of mainstream society.

Centers for Independent Living play a crucial role in the lives of people with disabilities, and work tirelessly to ensure that people with disabilities have a real choice in where and how they live, work, and participate in the community. Additionally, CILs are an excellent service and a bargain for America, keeping people engaged with their communities and saving taxpayer money. NCIL is dedicated to increasing the availability of the invaluable and extremely cost-effective services CILs provide, and they have submitted written testimony with a similar request. I strongly support NCIL's testimony.

THE **AIDS** INSTITUTE

WRITTEN STATEMENT OF
CARL SCHMID, DEPUTY EXECUTIVE DIRECTOR, THE AIDS INSTITUTE
TO THE SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES, EDUCATION,
AND RELATED AGENCIES
HOUSE COMMITTEE ON APPROPRIATIONS
APRIL 14, 2016

Dear Chairman Cole and Members of the Subcommittee:

The AIDS Institute, a national public policy, research, advocacy, and education organization, is pleased to offer comments in support of domestic HIV/AIDS and hepatitis programs in the FY2017 Labor, Health and Human Services, Education, and Related Agencies appropriation measure. We thank you for supporting these programs over the years, and hope you will do your best to adequately fund them in the future in order to provide for and protect the health of many Americans.

CDC Viral Hepatitis Prevention

The CDC estimates that there are 55,000 new hepatitis infections every year, with a 150 percent increase in new infections between 2010 and 2013. Nearly 5.3 million people are living with hepatitis B or hepatitis C. They are the leading causes of liver cancer, which is now one of the most lethal and fastest growing cancers in the United States. The CDC's Division of Viral Hepatitis (DVH) budget is nowhere near the estimated $170 million needed for DVH to reduce new hepatitis infections in the U.S. Only with increased funding can we provide the level of testing, education, and surveillance needed to reduce new infections and eliminate hepatitis in the U.S.

HIV/AIDS

A record 1.2 million people in the U.S. are living with HIV, and there are still 50,000 new infections each year. Persons of minority races and ethnicities are disproportionately affected. The rate of new infections in the African American community is eight times that of whites. HIV greatly affects low income people; nearly 90 percent of Ryan White Program clients have a household income of less than 250 percent of the Federal Poverty Level.

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

With the advent of antiretroviral medicines, HIV has turned from a near certain death sentence to a treatable chronic disease if people have access to consistent and affordable health care and medications. HIV treatment not only saves the lives of people with HIV, but also reduces HIV transmission. Therefore, HIV treatment is also HIV prevention. In order to realize these benefits, people with HIV must be diagnosed through testing, and linked to and retained in care and treatment. Diagnosing, treating, and achieving viral suppression for all individuals living with HIV are key elements to achieving the goals of the updated National HIV/AIDS Strategy, and to one day reaching an AIDS-free generation.

The Ryan White HIV/AIDS Program

The Ryan White HIV/AIDS Program, acting at the payer of last resort, provides medications, medical care, and essential coverage completion services to approximately 512,000

low-income, uninsured, and underinsured individuals with HIV. With people living longer and continued new diagnoses, the demands on the program continue to grow and many needs remain unmet. According to the CDC, only 39 percent of people living with HIV in the U.S. are retained in care, 36 percent have been prescribed antiretroviral treatment, and 30 percent are virally suppressed. With continued funding we can improve these numbers and health outcomes.

The AIDS Drug Assistance Program (ADAP) provides states with funds to pay for medications for over 262,000 people. While ADAPs continue to provide medications to Ryan White clients to keep them healthy, an increased amount of ADAP funding is being used to help low-income enrollees afford insurance premiums, deductibles, and high cost-sharing of their medications. We urge you to ensure that ADAP and the rest of the Ryan White Program receive adequate funding to keep up with the growing demand. With this increased demand for medications comes a corresponding increase in medical care and support services provided by all other parts of the program.

With the Affordable Care Act (ACA), there are expanded opportunities for health care coverage for some Ryan White clients. This will result in some cost shifting, but it will never be a substitute for the Ryan White Program. Nearly three-quarters of all clients already have some sort of coverage; over half through Medicaid and Medicare. Public and private insurance programs do not always provide the comprehensive array of services required to meet the needs of individuals living with HIV. Services critical to managing HIV include case management; mental health and substance use services; adult dental services; and transportation, legal, and nutritional support services. Because not all states are expanding Medicaid, benefits differ from state to state, and for many individuals living with HIV, the Ryan White Program is the only source of care and treatment. This approach of coordinated, comprehensive, and culturally

competent care leads to better health outcomes resulting in over 81 percent of Ryan White Program clients achieving viral suppression, an increase of over 17 percent since 2010.

The AIDS Institute urges the Committee to reject the President's budget proposal to eliminate dedicated funding for Part D of the Ryan White Program and transfer it to Part C. Part D serves women, infants, children, and youth with HIV and is a well-established system of care. Additionally, we support the President's request to increase by $9 million the Part F Special Projects of National Significance in order to increase HCV testing, and care and treatment for people living with HIV who are co-infected with HCV.

CDC HIV Prevention

We have made significant progress in the fight against HIV in the U.S. over the last 30 years. Due to past investments, we have averted thousands of new infections and lowered new infection rates among heterosexuals, people who inject drugs, and African Americans. However, some communities continue to experience increases, including gay, bisexual, and other men who have sex with men (MSM), particularly young blacks and Latinos. Averting all 50,000 new infections each year would result in approximately $20 billion in lifetime treatment costs.

With more people living with HIV than ever before, there are greater chances of HIV transmission. The CDC is focusing resources on those populations and communities most impacted, and investing in those programs that will prevent the most infections. With over 156,000 people living with HIV in the U.S. unaware of their infection, the CDC is also focused on increased HIV testing programs. Testing people early allows them to be diagnosed and referred to care and treatment earlier, which is critical to bettering individual health outcomes and preventing new infections. We support the Administration's proposal to allow health departments to spend a limited portion of their prevention funding on pre-exposure prophylaxis

(PrEP) and associated services, which has been proven to reduce the chances of HIV infection by up to 92 percent.

The CDC estimates that one in four new HIV infections are among young people between the age of 13 and 24; most of whom are young gay men. We must do a better job of educating all youth about HIV. Increasing funding to the HIV Division of Adolescent and School Health (DASH) will help achieve this goal.

Syringe Service Programs

We support continued federal funding for programs associated with syringe services in jurisdictions that are experiencing or are at risk for significant increases in HIV or hepatitis infections due to injection drug use.

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

While we have made great strides, there is still a long way to go for AIDS research. NIH has supported innovative basic science for better drug therapies, behavioral and biomedical prevention interventions, and has saved the lives of millions around the world. However, continued research is necessary to learn more about the disease and to develop new treatments and prevention tools. We look forward to an effective AIDS vaccine and eventual cure.

Minority AIDS Initiative

Finally, we ask the Committee to continue to support the Minority AIDS Initiative (MAI) in order to address the needs of some of the most vulnerable populations for HIV infection.

Again, we thank you for your continued support. We have made great progress, but we are still far from achieving an AIDS-free generation and eradicating viral hepatitis. We now have the tools, but we need continued leadership and the necessary resources. Thank you.

mama's kitchen

Nourishing the heart, one meal at a time.

Testimony Prepared by Alberto Cortes, Executive Director of Mama's Kitchen, for the United State House Committee on Labor, Health and Human Services, and Education, and Related Agencies addressed to the Department of Health and Human Services

April 15, 2015

Mama's Kitchen is part of a nationwide coalition, the Food is Medicine Coalition, of over 80 food and nutrition services providers, affiliates and their supporters across the country that provide food and nutrition services to people living with HIV/AIDS (PWH) and other chronic illnesses. In our service area, we provide 450,000 medically sensitive, home delivered meals annually. Collectively, the Food is Medicine Coalition is committed to increasing awareness of the essential role that food and nutrition services (FNS) play in successfully treating HIV/AIDS and to expanding access to this indispensable intervention for people living with other severe illnesses.

1.) Why Food and Nutrition Services (FNS) Matter for PWH

While adequate food and nutrition are basic to maintaining health for all persons, good nutrition is crucial for the management of HIV infection. Proper nutrition is needed to increase absorption of medication, reduce side effects, and maintain healthy body weight. Research has identified the virus as an independent risk factor for cardiovascular, liver and kidney disease, cancer, osteoporosis and stroke. Several HIV medications can cause nausea and vomiting and some can affect lab results that test lipids and kidney and liver function. These compounding health effects, caused by the virus and its medications, reinforce the important role a nutrient-rich diet plays in a patient's overall care plan. In addition, providing food and nutrition services can serve to facilitate access and engagement with medical care, especially among vulnerable populations.

The Food and Nutrition Services category within the Ryan White Program includes medical nutritional therapy (MNT) and food and nutrition services (FNS). MNT covers nutritional diagnostic, therapy, and counseling services focused on prevention, delay or management of diseases and conditions, and involves an in-depth assessment, periodic reassessment and intervention provided by a licensed, Registered Dietitian Nutritionist (RDN) outside of a primary care visit. The range of FNS provided through the Ryan White program complements the needs of PWH at any stage of their illness. For those who are most mobile, there are congregate meals, walk-in food pantries and voucher programs. For those whose disease has progressed, home-delivered meals and home-delivered grocery bags complement their medical treatment.

Since 2006, HRSA has included MNT and FNS, provided under the guidance of RDNs, as a clinically effective **core medical service** in the Ryan White Program. These services play a critical role in ensuring that PWH enter and continue in primary medical care, adhere to their medications, and ultimately achieve viral suppression.

address 3960 Home Avenue, San Diego, California 92105 ~ *phone* 619.233.6262 ~ *fax* 619.233.6283 ~ www.mamaskitchen.org

2.) FNS as a Care Completion Service Unique to Ryan White

Social and economic interventions, most often in the form of care completion service like food and nutrition services, are fundamental to making health care work for PWH. Support services for PWH are not covered in any comprehensive way by Medicaid or other public insurance initiatives that have been expanded by the Affordable Care Act. As the HIV epidemic in the United States increasingly impacts low-income individuals, support services help stabilize individuals living with or at risk of HIV. When needs are met, and life's emergencies are held at bay, PWH are poised to remain connected to care and treatment.

3.) Access to FNS and the Triple Aim

Access to appropriate food and nutrition services (FNS) are increasingly recognized as key to accomplishing the triple aim of national healthcare reform for PWH.

Better Health Outcomes

When clients get effective FNS and become food secure, they then keep scheduled primary care visits, score higher on health functioning, are at lower risk for inpatient hospital stays and are more likely to take their medicines[i]. Studies show both the health benefits of access to MNT and/or nutrition counseling for people with HIV infections[ii] and the resulting decreases in their healthcare costs. Compare these outcomes to PWH who are food insecure, who have:

- Lower CD4 counts & lower likelihoods of having undetectable viral loads[iii]
- More ER visits[iv] & increased morbidity and mortality[v]
- More missed primary care appointments & reduced use of antiretroviral therapy[vi].

Lower Healthcare Costs

Millions of dollars in healthcare expenditures are saved through the provision of FNS to PWH. A recent study comparing participants in a medically-tailored FNS program vs. a control group within a local managed care organization found that average monthly healthcare costs for PWH fell 80% in first three months after receiving FNS[vii]. If hospitalized, nourished clients' costs were 30% lower, their hospital length of stay was cut by 37% and they were 20% more likely to be able to be discharged to their homes rather than a more expensive institution[viii]. Furthermore, FNS are a very inexpensive intervention. For each day in a hospital saved, you can feed a person a medically-tailored diet for half a year.

Improved Patient Satisfaction

Studies show nutrition counseling improves quality of life[ix]. Members overwhelmingly report that our services help them live more independently, eat more nutritiously and manage their medical treatment more effectively.

4.) FNS and the National HIV/AIDS Strategy (NHAS)

Access to FNS for PWH is fundamental to fulfilling the goals of the NHAS.

- **NHAS Goal: Reducing new HIV infections:** PWH who are food insecure are less likely to have undetectable viral loads in a statistically significant way. Undetectable viral loads prevent transmission 96% of the time[x], thus, FNS is key to prevention[xi].
- **NHAS Goal: Increasing access to care and improving health outcomes for people living with HIV:** PWH who receive effective FNS are more likely to keep scheduled primary care

visits, score higher on health functioning, are at lower risk for inpatient hospital stays and are more likely to take their medicines[xii].

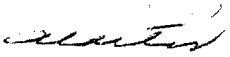
- **NHAS Goal: Reducing HIV-related disparities and health inequities:** By providing FNS to PWH who are in need largely because of poverty, we improve health outcomes, thereby reducing health disparities[xiii].
- **NHAS Goal: Achieving a more coordinated national response to the HIV epidemic:** There remains a tremendous variation by state in coverage of food and nutrition services both inside and outside of Ryan White, making support for Ryan White HIV Program all the more needed. Ultimately, if we are going to achieve a more coordinated national response to the HIV epidemic and our quest to reduce healthcare spending nationwide, FNS must be included in all healthcare reform efforts, including Ryan White and the ACA.

Conclusion

We are deeply aware of the difficult decisions that face the members of the Committee in the current fiscal environment. Yet, research shows that investment in FNS, with the great return in prevention and retention in HIV care, are vital to lowering the number of new infections in the domestic HIV epidemic and ultimately reducing healthcare costs and preserving healthcare resources for the future. A client's diet can literally have life and death consequences. When people are severely ill, good nutrition is one of the first things to deteriorate, making recovery and stabilization that much harder, if not impossible. Early and reliable access to medically-appropriate FNS helps PWH live healthy and productive lives, produces better overall health outcomes and reduces health care costs.

Along with our colleagues, we appreciate the opportunity to offer this testimony regarding the FY 2017 Appropriations process. We are also pleased to offer our assistance and expertise, including information from our Research Library.

Thank you.



Alberto R. Cortés
Executive Director
Mama's Kitchen
3960 Home Avenue
San Diego, CA 92105
619-233-6262
alberto@mamaskitchen.org

---

[i] Aidala A, Yomogida M, Vardy Y & the Food & Nutrition Study Team. Food and Nutrition Services, HIV Medical Care, and Health Outcomes. New York State Department of Health: Resources for Ending the Epidemic, 2014. Available at https://www.health.ny.gov/diseases/aids/ending_the_epidemic/docs/key_resources/housing_and_supportive_services/chain_factsheet3.pdf

[ii] Academy of Nutrition and Dietetics (formerly American Dietetic Association). HIV/AIDS Nutrition Evidence Analysis Project at http://www.adaevidencelibrary.com/conclusion.cfm?conclusion_statement_id=250707 Accessed 29 July 2012.

[iii] Aidala A., Yomogida M., and the HIV Food & Nutrition Study Team (2011);
Singe AW,Weiser SD, McCoy, SI. Does Food Insecurity Undermine Adherence to Antiretroviral Therapy? A Systematic Review. AIDS Behav (2015) 19:1510–1526.
[iv] Ibid.
[v] Anema A, Chan K, Yip B, Weiser S, Montaner JSG, Hogg RS. Impact of food insecurity on survival among HIV-positive injection drug users receiving antiretroviral therapy in a Canadian cohort. 141st APHA Annual Meeting, Nov. 2-6, 2013. Boston, MA. Abstract #: 290277
[vi] Aidala A., Yomogida M., and the HIV Food & Nutrition Study Team (2011).
[vii] Gurvey J, Rand K, Daugherty S, Dinger C, Schmeling J, Laverty N. Examining Health Care Costs Among MANNA Clients and a Comparison Group. J Prim Care Community Health. (2013) 4:311-317
[viii] Ibid.
[ix] Rabeneck L, Palmer A, Knowles JB, Seidehamel RJ, Harris CL, Merkel KL, Risser JMH, Akrabawi SS. A randomized controlled trial evaluating nutrition counseling with or without oral supplementation in malnourished HIV-infected patients. J Am Diet Assoc. (1998) 98: 434-438;Schwenk A, Steuck H, Kremer G. Oral supplements as adjunctive treatment to nutritional counseling in malnourished HIV-infected patients: randomized controlled trial. Clinical Nutrition (1999) 18(6): 371-374.
[x] M. S. Cohen *et al.*, Prevention of HIV-1 Infection with Early Antiretroviral Therapy. N. Engl. J. Med.(2011) 365, 493-505 . HPTN 052
[xi] Palar K, Laraia B, Tsai A, Weiser SD Food insecurity is associated with sexually transmitted infections and HIV serostatus among low income adults in the National Health and Nutrition Examination Survey (NHANES) (1999-2010). Presented at the American Public Health Association 141st Annual Meeting, Boston, MA, November 5, 2013.
[xii] Aidala A, Yomogida M, Vardy Y & the Food & Nutrition Study Team. Food and Nutrition Services, HIV Medical Care, and Health Outcomes. New York State Department of Health: Resources for Ending the Epidemic, 2014. Available at
xiii Weiser SD, Frongillo EA, Ragland K, Hogg RS, Riley ED, Bangsberg DR. Food insecurity is associated with incomplete HIV RNA suppression among homeless and marginally housed HIV-infected individuals in San Francisco. J Gen Intern Med. (2009) 24(1):14-20.

Helen Keller
INTERNATIONAL

352 Park Avenue South
Suite 1200
New York, NY 10010
212-532-0544
212-532-6014 fax
info@hki.org

KATHY SPAHN
PRESIDENT AND CHIEF EXECUTIVE OFFICER
HELEN KELLER INTERNATIONAL

SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES, EDUCATION AND RELATED AGENCIES
COMMITTEE ON APPROPRIATIONS
U.S. HOUSE OF REPRESENTATIVES

APRIL 15, 2016

Mr. Chairman, thank you for this opportunity to provide testimony to the Subcommittee on behalf of Helen Keller International's ChildSight® program. My name is Kathy Spahn, and I serve as the President and Chief Executive Officer of Helen Keller International (HKI). I am requesting that this Subcommittee recommend in its fiscal year 2017 Appropriations report that the Department of Education provide funding for programs that identify and provide prescription eyeglasses to children from low income families whose educational performance and future vocational success may be hindered because of poor vision.

It is HKI's hope that with the continued support of the Department of Education and private donors we can deliver free vision screenings and eyeglasses to thousands of economically disadvantaged children who have extremely limited access to immediate and affordable vision care.

CHILDSIGHT®

Established in 1994, ChildSight® tackles the common problem of refractive error among children and adolescent students in underserved communities in the United States. More commonly known as nearsightedness, farsightedness, and astigmatism, refractive error affects one in four children and adolescents nationwide.

The mission of ChildSight® is to improve the vision and academic potential of economically disadvantaged children. Research has established a clear link between vision and learning. Most learning platforms – books, computer screens, blackboards and classroom presentations – require clear vision in order for a child to interact, assimilate information and respond. Yet in thousands of classrooms, millions of children are unable to make the most of their education simply because they cannot see well. This is especially tragic since most cases of poor vision are due to refractive error and are easily corrected.

If not detected and treated promptly, refractive error and other eye conditions can lead to long term visual deficiencies and developmental problems. Students must have clear, healthy eyesight in order to fully focus on schoolwork and classroom lessons or the opportunity to gain a valuable education is severely diminished. Adults whose visual impairment denied them the chance to gain core academic skills are at a disadvantage in seeking employment and achieving economic independence.

In most cases, the solution is simple: the provision of correctly prescribed eyeglasses. ChildSight® helps students directly by going into the schools to conduct vision screenings, identifying children with refractive error and providing prescription eyeglasses to address this need, all free of charge. In so doing, ChildSight® "brings education into focus™" for children who would otherwise be left with untreated vision problems – and lost opportunities. Millions of students do not get the care they need due to limited access to vision screening and the prohibitive cost of a pair of prescription eyeglasses. ChildSight® targets these communities and serves at-risk children by providing free on-site screening, free eyeglasses and follow-up care so that students can focus in the classroom in order to achieve their potential for future academic and vocational success.

ChildSight® is distinguished by its high clinical standards and its efforts to educate children and their families about the importance of corrected vision and the availability of related healthcare resources in their community. ChildSight® provides direct access to vision screening and refraction by a licensed optometrist who prescribes the necessary lenses for each child.

ChildSight® goes one step further. Students identified with potentially severe eye conditions beyond basic refractive error are referred to our partnering ophthalmologists for a full eye exam and follow-up treatment as needed. This final step ensures that children who need further assessment and care will be able to receive it.

ChildSight® also addresses the needs of out of school youth. Services are offered to runaway and homeless youth, in partnership with organizations like Covenant House and the Ali Forney Center in New York, and for high school dropouts seeking to pass the General Educational Development (GED) test. By addressing the eye care needs of vulnerable youth, ChildSight® helps to reintegrate these young people into the educational system and enables them to seek and maintain employment.

POSITIVE RESULTS

Since its inception, ChildSight® has screened over 1.7 million children and delivered over 243,000 pairs of free eyeglasses to children in need, with support from this Subcommittee, the Department of Education and private donations. We have seen the positive results of the ChildSight® program.

Teachers we have surveyed throughout the country report that a majority of students who had their vision corrected with ChildSight® eyeglasses exhibited significant improvement in the completion of schoolwork and homework; increased class participation and a reduction in

disruptive behavior; and improvement in grades, self-confidence and self-perception as reported by the teachers.

PUBLIC/PRIVATE UNDERTAKING

ChildSight® is truly a public/private endeavor. The program's success is due in large part to the dedication and commitment of our partner physicians, educators, community activists and business people in each of our local sites. With their support and the contributions of foundations and corporations, we continue to seek the institutionalization and long term sustainability of our programs. Government funding is also crucial to achieving long term sustainability and expanding access. For example, a recent grant from the City of New York has supported the integration of ChildSight® eye health services into a package of social and health services offered at designated *Community School* locations in the Bronx.

The endorsement and support of the Department of Education have played an integral role in our ability to leverage committed support from the private sector. ChildSight® has received significant long term funding from foundations including The Community Foundation for Greater New Haven, Lavelle Fund for the Blind, Mt. Sinai Health Care Foundation, The New York Community Trust, Children's Aid Society, The Rose Hills Foundation, Victoria Foundation, The Healthcare Foundation of New Jersey, and Reader's Digest Partners for Sight Foundation.

Local health care professionals, such as optometrists, pediatric ophthalmologists and opticians, at our program sites are members of the ChildSight® team who help us meet the vision care needs of the students we serve. ChildSight® contracts with ophthalmic clinics and optical shops selected according to their strong professional credentials. The services of these community professionals are either donated or provided at a reduced, reasonable rates.

CONCLUSION

ChildSight® provides an invaluable – and often life changing – service to local youth in a pragmatic and cost-effective manner. Of particular concern is the need to reach at-risk children and provide them free screening, free eyeglasses and free follow-up care.

I ask this Subcommittee to recommend in its fiscal year 2017 Committee report that the United States Department of Education support programs that provide vision care for children from economically disadvantaged families. These Department of Education funds will support ongoing programs and will provide vision screening and prescription eyeglasses for such children.

Corrective treatment eye treatment is needed to overcome the economic, social and transportation barriers that prevent many children from economically disadvantaged families from obtaining the vision care they need. Students with corrected vision can focus in the classroom in order to achieve their potential for academic and vocational success

As our founding board member Helen Keller said: *We are never really happy until we try to brighten the lives of others.*

Testimony Prepared for the House Subcommittee on Labor, Health and Human Services, and Education and Related Agencies

Fiscal Year 2017 Appropriations for the Health Resources and Services Administration's Title VII Health Professions Program and Related Priorities

Submitted for the Record by the American Academy of PAs

April 15, 2016

Contact: Sandy Harding, MSW, Senior Director of Federal Advocacy

sharding@aapa.org/(571) 319-4338

On behalf of more than 108,500 nationally-certified PAs (physician assistants), the American Academy of PAs (AAPA) is pleased to submit comments on the Fiscal Year 2017 appropriations for the Departments of Labor, Health and Human Services, and Education and related agencies. AAPA respectfully requests the Subcommittee to approve funding of $280 million for the Title VII health professions education program administered by the Health Resources and Services Administration (HRSA) and provide $12 million of the funding allocated to the Primary Care Training and Enhancement program (PCTE) for PA education programs. Additionally, AAPA supports continued funding for the National Health Service Corps (NHSC), community health centers (CHCs), and activities within the Substance Abuse and Mental Health Services Administration (SAMHSA) which use PAs to increase access to treatment for mental illnesses and substance use disorders.

PA Education and Practice

PAs receive a broad education over approximately 27 months which consists of two parts. The didactic phase includes coursework in anatomy, physiology, biochemistry, pharmacology, physical diagnosis, behavioral sciences, and medical ethics. This is followed by the clinical phase, which includes rotations in medical and surgical disciplines such as family medicine, internal medicine, general surgery, pediatrics, obstetrics and gynecology, emergency medicine, and psychiatry. Due to these demanding rotation requirements, PA students will have completed at least 2,000 hours of supervised clinical practice in various settings and locations by graduation.

There are currently 210 accredited PA educational programs in the U.S., all of which are located within schools of medicine or health sciences, universities, teaching hospitals, and the Armed Services. The majority of these programs award a master's degree. PAs must pass the Physician Assistant National Certifying Examination and be licensed by a state in order to practice. The PA profession is the only medical profession that requires a practitioner to periodically take and pass a high-stakes comprehensive exam to remain certified, which PAs must do every ten years.

To maintain their certification, PAs must also complete 100 hours of continuing medical education (CME) every two years.

PAs practice and prescribe medication in all 50 states, the District of Columbia, and all U.S. territories with the exception of Puerto Rico. They manage the full scope of patient care, often handling patients with multiple comorbidities. In their normal course of work, PAs conduct physical exams, order and interpret tests, diagnose and treat illnesses, assist in surgery, and counsel on preventative healthcare. The rigorous education and clinical training of PAs enables them to be fully qualified and equipped to care for patients in every medical and surgical specialty and setting.

PAs and Title VII Funding

Title VII of the Public Health Service (PHS) Act is the only continuing federal funding available to PA educational programs. As a result, AAPA supports increased funding for Title VII, particularly for PA education grants funded through PCTE. These grants have proven successful in training new PAs; for instance, the Physician Assistant Training in Primary Care program supported the education of 4,390 PA students in the 2014-2015 school year (up from 4,071 in 2013-2014). Of those students, 29% were minorities and/or from disadvantaged backgrounds, and 13% were from rural areas. Fifty-eight percent of the institutions which were awarded grants through this program were focused on primary care, and the majority of them were in rural or medically underserved areas.

Likewise, the Expansion of Physician Assistant Training (EPAT) program under PCTE assisted 429 students during the 2014-2015 school year (equal to 2013-2014), with 48% of these students receiving training in a medically-underserved area. EPAT funds support PA students in covering the cost of tuition, fees, and training and fellowships for up to two years. 130 students supported by these grants graduated in 2015 – of these, 36% intended to practice in a medically underserved area, 22% wished to practice in a rural community, and 73% planned to work in primary care. These statistics clearly show that both programs have lived up to their intended purposes: encouraging students from under-represented groups to attend PA school and increasing PA practice in rural and medically underserved areas.

Title VII has been instrumental in allowing increased numbers of PA students to pursue their education. However, this funding has also helped PA programs expand opportunities for clinical rotations in rural and medically underserved areas. This expansion benefits PA students, but just as important, it benefits local residents who would otherwise have limited access to healthcare providers. It is common for new PAs to remain in the area in which they completed their education, and a review of PA graduates from 1990-2009 showed that PAs who graduated from programs supported by Title VII were 47% more likely to work in rural health clinics than graduates of other programs. Continued funding for PA educational programs under Title VII is a win-win scenario for underserved communities and the nation's healthcare workforce.

PAs in Primary Care

Currently, 30% of practicing PAs work in primary care settings, and PAs are one of three primary care providers along with physicians and nurse practitioners (NPs) who may participate in NHSC. There are now more than 9,200 clinicians participating in NHSC's loan repayment and scholarship programs – 12% of which are PAs. In light of the demand for providers in the rural and medically underserved areas which are covered by NHSC, as well as the ongoing primary care provider shortage, continued funding is needed to ensure this important program can reach patients who lack access to care and help grow the next generation of healthcare providers in places where they are needed most.

PAs also provide medical care in community health centers (CHCs), and in some cases, serve as CHC medical directors. CHCs offer cost-effective healthcare throughout the country and serve as medical homes for millions of patients who live in medically underserved areas. CHCs provide a wide variety of healthcare services through team-based care, providing high quality care to CHC patients and significantly reducing their medical expenses by focusing on primary care services. AAPA supports continued funding for both NHSC and CHCs.

PAs in Mental Health and Addiction Medicine

PAs typically work on the "front lines" of healthcare and they often treat patients who are experiencing mental illnesses or addiction, even when they do not specialize in these areas. AAPA is pleased HRSA acknowledged the role of PAs in the mental healthcare and addiction medicine spaces in its FY17 budget request by including them in the definition of "behavioral health workforce." We support efforts in the budget request to further integrate primary care and behavioral healthcare by encouraging the use of screenings, referrals, and warm handoffs to specialists in the same facility or via telemedicine services, all of which have been shown to improve patient outcomes and mitigate gaps in coverage caused by too few providers.

Additionally, we are pleased both Congress and the Administration are focused on addressing the shortage of treatment options for individuals who are struggling with opioid addiction. AAPA supports funding for programs intended to allow additional healthcare providers – including PAs – to prescribe buprenorphine as a part of medication-assisted treatment (MAT). The Administration has proposed in its budget a demonstration program to gauge the feasibility of making this change, even though the majority of these providers, including PAs, can already prescribe this drug for pain management purposes. Instead, we believe it is necessary for Congress to pass a statutory fix to the Drug Addiction Treatment Act of 2000 (DATA 2000) which would remove the federal ban on PAs prescribing buprenorphine for MAT. A demonstration project is an unnecessary step that only slows down bringing in more providers to assist with this crisis.

Summary

AAPA recognizes the fiscal challenges facing the country, and we understand tough choices must be made in allocating scarce federal dollars to our nation's varied priorities. Yet, HRSA has estimated there could be a shortage of more than 20,000 physicians by 2020. The PA profession continues to experience record growth - the profession grew 36.4 percent between 2009 and 2014 - with historically high numbers of PAs currently practicing in the U.S. We believe better utilization of PAs – particularly in rural and medically underserved areas – is an important way to mitigate these projections and ensure all Americans have access to high quality healthcare. As such, AAPA urges continued federal support for programs which support PAs and PA students.

We appreciate the opportunity to present our views during the FY17 appropriations process, and we welcome the opportunity to serve as a resource to the Subcommittee. If you have any questions, please do not hesitate to have your staff contact Sandy Harding, AAPA Senior Director of Federal Advocacy, at 571-319-4338 or sharding@aapa.org.

Daniel R. Hawkins, Jr.
Senior Vice President, Public Policy and Research
National Association of Community Health Centers
1400 Eye Street NW, Suite 910
Washington, DC 20005

Testimony to the House Appropriations Subcommittee on
Labor, Health and Human Services, Education, and Related Agencies

Introduction

Chairman Cole, Ranking Member DeLauro, and Members of the Subcommittee: on behalf of our nation's community health centers, we wish to thank you for the opportunity to submit testimony for the record as you consider the Fiscal Year (FY) 2017 Labor-Health and Human Services-Education and Related Agencies Appropriations bill.

Health Centers- General Background

For over 50 years, health centers have been operating as community-owned, non-profit entities providing primary medical, dental, and behavioral health care as well as pharmacy and a variety of enabling and support services to patients and communities in need. In 2014, over 1,300 health center organizations served more than 9,000 urban and rural communities nationwide, serving as the "health care home" for more than 24 million patients, including nearly 7 million children and nearly 300,000 veterans. Health centers operate in all 50 states, the District of Columbia, all U.S. Territories, and nearly every Congressional district.

By statute and mission, health centers are located in medically underserved areas (or serve medically underserved populations) and are governed by patient-majority boards to ensure they are responsive to the needs of each individual community they serve. Health centers offer comprehensive care to all residents of the community, regardless of ability to pay or insurance status, and offer services on a sliding fee scale. Health centers' unique model of care has resulted

in savings to the entire health system of approximately $24 billion annually. Health center care reduces preventable hospitalizations and emergency department (ED) use, as well as the need for more expensive specialty care. The services provided at health centers save $1,263 per patient per year when compared to expenditures for non-health center patients.

In addition to reducing costs, health centers also serve as small businesses and economic drivers in their communities. Health centers employ over 175,000 individuals and generate an estimated $26.5 billion in needed economic activity for communities that need it the most.

FY 2016 Funding Background

We want to thank the members of this Subcommittee for their strong support of health centers within the Consolidated and Further Continuing Appropriations Act of 2016 to ensure health center funding continues to reach communities in need. In FY 2016, the Health Centers program received a total of $5.1 billion in total federal funding. This includes $1.49 billion in discretionary funding provided by the Subcommittee and $3.6 billion in mandatory funding for health centers through the continuation of Community Health Center Fund in H.R. 2, the Medicare Access and CHIP Reauthorization Act of 2015 (MACRA).

FY 2017 Funding Request

Thanks to investments by Congress and with support from this Subcommittee, health centers have doubled the number of patients served since 2000 and expanded to new communities. Since 2005, health centers have gone from serving one in five Americans living in poverty to one in four, and today serve a higher proportion of the uninsured than at any time in the last ten years. In addition to serving more people and communities, health centers are offering an increasingly comprehensive range of services on-site – 81% now offer mental health and/or substance abuse treatment, 77% offer oral health, and 40% offer pharmacy. However,

continued investment is needed to make each health center a truly integrated "one-stop shop" for patient care.

Therefore, health centers are respectfully requesting Congress and this Subcommittee ensure funding for the Health Centers Program remains whole and does not suffer any funding reductions in FY2017, within either the discretionary or mandatory funding streams. This includes rejecting proposals to shift funds to mandatory spending with a corresponding reduction in discretionary funding below FY16 levels. Continued funding for the Health Centers Program at the FY2016 program level of $5.1 billion is consistent with the levels outlined on an overwhelmingly bipartisan basis in MACRA and will preserve the high quality cost-effective primary care offered today at health centers across the country.

We also have support from a record number of Members of Congress for continued health center funding. In March, 308 House members signed a letter led by Reps. Gus Bilirakis (R-FL) and Gene Green (D-TX) to this Subcommittee as part of the annual appropriations process. The letter highlighted the important role of health centers in providing primary care and their proven track record of success in fostering innovation and cost savings within the health care system. A copy of the letter can be viewed here: http://www.nachc.com/client//FINAL%20FY17%20Community%20Health%20Centers%20Letter.pdf

Leveraging Investments in Access with a Robust Clinical Workforce

As the health center model has grown and evolved to meet the increasingly complex needs for care in underserved communities, combating workforce shortages has been a constant battle for health centers. Though the ranks of health center clinical care staff have nearly doubled since 2000, workforce shortages are limiting the ability of individual health centers to

serve as many patients as they could if fully staffed. A recent report issued by NACHC focusing on clinical workforce needs, entitled *Staffing the Safety Net: Building the Primary Care Workforce at America's Health Centers*, found that virtually all health centers are experiencing at least one clinical vacancy and that 70 percent of health centers say they currently have at least one vacancy for a family physician. The crucial finding related to how much further health centers collectively could leverage federal investments: according to their own projections, if fully staffed, health centers could serve an additional two million patients.

Addressing the workforce needs of health centers is a major factor in providing high quality care to all patients. Health centers work synergistically with the National Health Service Corps (NHSC) to address staffing needs, but are also working to "grow our own" workforce though residency training programs at health centers including through Teaching Health Centers and Nurse Practitioner Residency Training Programs. However, while roughly half of all National Health Service Corps clinicians serve in health centers, many health centers still cannot gain access to NHSC providers due to insufficient funding for the program. We feel now, more than ever, is the time for sustainable investments by Congress in order for health centers to meet existing and future demands for care. We urge the Subcommittee to fund the National Health Service Corps at the President's Budget request of $380 million, to provide scholarships and loan repayment to thousands more clinicians.

Of course, we are also looking towards the end of FY2017 when funding provided under MACRA for the Health Center Fund is set to expire again. Without Congressional action, health centers will once again face a 70 percent reduction of funding. A reduction in funding of that magnitude will directly impact every health center in nearly every Congressional district. When facing this potential reduction in 2015, we estimated 7.4 million patients would have lost access

to care at their local health center and nearly 57,000 clinicians and other staff would have lost their jobs—given recent investments called for by Congress, these numbers would almost surely be higher if this funding were to expire next year. We strongly believe the federal investments that support the health center system of care must be sustained and stabilized to ensure access to care is not disrupted. To that end, we look forward to working with the members of the Subcommittee to ensure the "Health Center Funding Cliff" will not occur. We urge Congress to take action well before the September 2017 expiration of the Health Center Fund to make the Health Centers Fund permanent and reduce the uncertainty caused by year-by-year renewals of this critical investment in access to care.

Conclusion

As the FY2017 appropriations process moves forward, we urge you to maintain current funding levels for our nation's health centers. Despite the progress made in expanding the program in recent years, health centers continue to see unmet need in our communities and are experiencing increased demand. Though some health center patients have gained insurance, this doesn't automatically translate into meaningful access to care. Health centers are still serving a large number of under-insured patients, as well as those who remain uninsured. We are extremely grateful for your past support and ask for the Subcommittee's continued support for the Health Centers Program. We look forward to working with you and thank you for your consideration.

Written Testimony of Mark Shriver
President
Save the Children Action Network (SCAN)
For the House Committee on Appropriations
Subcommittee on Labor, Health and Human Services, Education, and Related Agencies

April 15, 2016

Chairman Cole, Ranking Member DeLauro, 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 President of Save the Children Action Network (SCAN). SCAN is a national, non-profit organization that aims to mobilize all Americans to support critical investments in early childhood education.

For the Fiscal Year (FY) 2017 Labor, Health and Human Services, Education and Related Agencies Appropriations bill, SCAN supports:

- $3.4 billion for Child Care and Development Block Grants (CCDBG)
- $10.1 billion of Head Start and Early Head Start
- $350 million for Preschool Development Grants
- $1.3 billion for 21st Century Community Learning Centers
- $27 million for Innovative Approaches to Literacy

Background

Early Childhood Education (ECE) programs are critical for children. During the first five years of life, a child develops many of the skills necessary to become successful. It is during these years that they build the foundation for reading, math, science and academics, as well as the skills necessary for character building, social-emotional growth, gross-motor development, and executive functioning—including everything from impulse control to problem solving.

Unfortunately, two out of five American children are not enrolled in preschool. Without access to high quality early learning programs, children fall behind. Many never catch up. By age five, more than half of all American children are not prepared for school.[i]

Early education—starting at birth and continuing until a child's first day in kindergarten—is a critical window for ensuring future academic achievement. This window, however, closes quickly, and children who enter kindergarten unprepared are more likely to experience serious negative social impacts. Disadvantaged children who don't participate in high quality early education programs are:

- 70 percent more likely to be arrested for a violent crime; and
- 60 percent more likely to never attend college;
- 50 percent more likely to be placed in special education;
- 40 percent more likely to become a teen parent.[ii]
- 25 percent more likely to drop out of school;

Additionally, there are strong social and economic benefits to high quality ECE programs, including improved social skills and significant gains in literacy, language and math and a return on investment of $7 for every $1 invested.[iii,iv] It is critical to ensure that access to high-quality preschool and comprehensive early education and family engagement programs are available for all children regardless of their income.

Save the Children's Work on Early Childhood Education

Save the Children has long been a part of the movement to improve early childhood education in the United States. To advance early learning, Save the Children supports education programs for children at home and in the classroom. Our child experts work to ensure that our nation's most underserved children have the best chance for success. Every day, we help children get ready to learn and succeed in school and live healthy, active lives.

Save the Children's Early Steps to School Success (ESSS)

ESSS has been serving children in the United States since 2006. In 2014, more than 7,200 children and their families across 14 states and the District of Columbia participated in Save the Children's Early Steps to School Success program. The vast majority of these children are growing up in poverty and facing many hurdles to success. Despite their challenges, more than 80 percent of the children in the program score at or above the normal range for vocabulary acquisition and enter kindergarten on par with their middle-income peers, ready to succeed in school and in life.

Save the Children Early Head Start and Head Start Programs

Children who participate in federally-funded Head Start and Early Head Start have a higher likelihood of graduating high school and a lower likelihood of being charged with a crime than similar children who do not participate in Head Start.[v] Furthermore, participation in Head Start has been shown to close over one-third of the gap in test scores between children who participate in Head Start and their more advantaged peers.[vi] Three-year olds who participate in Early Head Start perform significantly better on cognitive, language and social-emotional measures than their peers.[vii] In 2015, through these programs, Save the Children reached tens of thousands of American children with early education services.

A recent review of programs operated under Maternal, Infant and Early Childhood Home Visiting Program (MIECHV) found various positive outcome measures.[viii] Research shows that high quality, rigorous home visiting programs result in improved child development and school readiness as well as improved family economic self-sufficiency. [ix] A leading model shows significant outcomes in reducing rates of state-verified reports of child abuse and neglect.[x]

Appropriations Priorities

Child Care and Development Block Grant (CCDBG)

The bipartisan reauthorization of CCDBG was a crucial moment for children and their families. Unfortunately, without significant new funding, states may be forced to make difficult decisions such as cutting the number of children receiving child care assistance or reducing payments to already low-paid child care providers.

Making matters worse, federal and state child care spending has fallen to an 11-year low and the number of children receiving assistance is at a 16-year low. Between 2006 and 2014, more than

364,000 children lost federal child care assistance. Only Oregon reimburses child care providers who serve children receiving child care assistance at the federally recommended level. Without the requested, new funding for CCDBG, fewer families will be able to receive the help they need affording child care, providers will be further deprived of the resources they need to support high-quality care, and the goals of the CCDBG reauthorization will go unfulfilled.

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. At the current level of funding, Head Start is only able to serve roughly two out of every five eligible preschoolers. Proposals for more Head Start programs to provide full-day, full-year services would help ensure our lowest-income children receive a strong early learning experience. This change, however, will require additional investments so that the additional 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 five percent of eligible infants and toddlers. The increased funding request is required to expand access to this life changing program.

Preschool Development Grants
Currently, fewer than three in ten four-year-olds participate in a high-quality preschool program. Funding to encourage states to establish or expand their own prekindergarten programs to serve more children and bolster the quality of these programs is critical. This program has already served over 70,000 children who otherwise would not have had access to pre-school. In the next two years, it is estimated that an additional 100,000 children will gain access to these vital programs. States' commitment to increasing access to high-quality preschool opportunities is extremely strong, as is their eagerness to partner with the federal government in this endeavor. Congress should match their enthusiasm and provide states with the resources they need.

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 the Every Student Succeeds Act, 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.

Innovative Approaches to Literacy (IAL)
The IAL program supports high-quality programs designed to develop and improve literacy skills for children and students from birth through 12th grade in high-need schools and underserved communities. These innovative programs promote early literacy for young children, motivate older children to read, and increase student achievement by using school libraries, pediatricians, and national nonprofit organizations as partners to improve childhood literacy.

IAL is the primary source of federal funding for school libraries and childhood literacy programs. Focusing on low income communities, these funds help many schools bring their school libraries up to standards and provide at-risk children with access to literacy programs. This money is not enough to help every child, but it does provide some support for disadvantaged schools to update materials and equipment, allowing children to have school library services and gain skills to become college and career ready.

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 FY16 appropriations process, and ask that you make a robust investment in early childhood education in FY17. 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.

---

[i] Julia B. Isaacs, "Starting School at a Disadvantage: The School Readiness of Poor Children," *Center on Children and Families at Brookings*, (March 2012).

[ii] "Early Childhood Education in the U.S.," Save the Children USA, (2015), Print.

[iii] James Heckman, Seong Hyeok Moon, Rodrigo Pinto, Peter Savelyev, and Adam Yavitz, "A New Cost-Benefit and Rate of Return Analysis for the Perry Preschool Program: A Summary," *NBER Working Paper Series*, (2010), http://jenni.uchicago.edu/papers/Heckman_Moon_etal_2010_NBER_wp16180.pdf.

[iv] *Investing in Our Future: The Evidence Base on Preschool Education*, Foundation for Child Development & Society for Research in Child Development, (Oct. 2013), http://fcd-us.org/sites/default/files/Evidence%20Base%20on%20Preschool%20Education%20FINAL.pdf.

[v] Eliana Garces, Duncan Thomas, and Janet Currie, "Longer-Term Effects of Head Start," *The American Economic Review*, 92.4, (Sept. 2002), http://www.jstor.org/stable/3083291?seq=1#page_scan_tab_contents.

[vi] Janet Currie and Duncan Thomas, "Does Head Start Make a Difference?" *The America Economic Review*, (1995): 359, http://www.econ.ucla.edu/people/papers/Currie/Currie14.pdf.

[vii] *Early Head Start Benefits Children and Families*, Early Head Start National Resource Center, An Office of the Administration for Children and Families, (June 2015), http%3A%2F%2Feclkc.ohs.acf.hhs.gov%2Fhslc%2Ftta-system%2Fehsnrc%2Fabout-ehs%23benefits.

[viii] Sarah Avellar, Diane Paulsell, Emily Sama-Miller, Patricia Del Grosso, Lauren Akers, and Rebecca Kleinman, "Home Visiting Evidence of Effectiveness Review: Executive Summary," *Office of Planning, Research and Evaluation, Administration for Children and Families, U.S. Department of Health and Human Services*, (2014): 9, http://homvee.acf.hhs.gov/HomVEE_Executive_Summary_2014-59.pdf.

[ix] Kimberly Boller, Deborah Daro, Patricia Del Grosso, Russell Cole, Diane Paulsell, Bonnie Hart, Brandon Coffee-Borden, Debra Strong, Heather Zaveri, and Margaret Hargreaves, *Making Replication Work: Building Infrastructure to Implement, Scale-up, and*

Sustain Evidence-Based Early Childhood Home Visiting Programs with Fidelity (Princeton, NJ: Mathematica Policy Research, 15 June 2014), http://www.mathematica-mpr.com/our-publications-and-findings/publications/making-replication-work-building-infrastructure-to-implement-scaleup-and-sustain-evidence.

[x] "Evidentiary Foundations of Nurse-Family Partnership," *Nurse Family Partnership*, (2011), http://www.nursefamilypartnership.org/assets/PDF/Policy/NFP_Evidentiary_Foundations.aspx.

Testimony Prepared by Karen Pearl, President & CEO of God's Love We Deliver for the United State House Subcommittee on Labor, Health and Human Services, Education, and Related Agencies addressed to the Department of Health and Human Services

April 15, 2015

We are pleased to submit this testimony to the Members of this Subcommittee on the urgency of continuing to support the Ryan White Program through the Appropriations process and increasing funding for the domestic HIV/AIDS portfolio in Fiscal Year 2017 (FY17). This support and funding will be decisive for achieving the goals of the National HIV/AIDS Strategy (NHAS) 2020, the AIDS Free Generation and halting the devastating effects of the HIV Treatment Cascade.

God's Love We Deliver is part of a nationwide coalition, the Food is Medicine Coalition, of food and nutrition services providers, affiliates and their supporters across the country that provide food and nutrition services to people living with HIV/AIDS (PWH) and other chronic illnesses. In our service area, we provide 1.5 million medically tailored, home delivered meals annually. Collectively, the Food is Medicine Coalition is committed to increasing awareness of the essential role that food and nutrition services (FNS) play in successfully treating HIV/AIDS and to expanding access to this indispensable intervention for people living with other severe illnesses.

1.) Why Food and Nutrition Services (FNS) Matter for PWH

While adequate food and nutrition are basic to maintaining health for all persons, good nutrition is crucial for the management of HIV infection. Proper nutrition is needed to increase absorption of medication, reduce side effects, and maintain healthy body weight. Research has identified the virus as an independent risk factor for cardiovascular, liver and kidney disease, cancer, osteoporosis and stroke. Several HIV medications can cause nausea and vomiting and some can affect lab results that test lipids and kidney and liver function. These compounding health effects, caused by the virus and its medications, reinforce the important role a nutrient-rich diet plays in a patient's overall care plan. In addition, providing food and nutrition services can serve to facilitate access and engagement with medical care, especially among vulnerable populations.

The Food and Nutrition Services category within the Ryan White Program includes medical nutritional therapy (MNT) and food and nutrition services (FNS). MNT covers nutritional diagnostic, therapy, and counseling services focused on prevention, delay or management of diseases and conditions, and involves an in-depth assessment, periodic reassessment and intervention provided by a licensed, Registered Dietitian Nutritionist (RDN) outside of a primary care visit. The range of FNS provided through the Ryan White program complements the needs of PWH at any stage of their illness. For those who are most mobile, there are congregate meals,

walk-in food pantries and voucher programs. For those whose disease has progressed, home-delivered meals and home-delivered grocery bags complement their medical treatment.

Since 2006, HRSA has included MNT and FNS, provided under the guidance of RDNs, as a clinically effective **core medical service** in the Ryan White Program. These services play a critical role in ensuring that PWH enter and continue in primary medical care, adhere to their medications, and ultimately achieve viral suppression.

2.) FNS as a Care Completion Service Unique to Ryan White

Social and economic interventions, most often in the form of care completion service like food and nutrition services, are fundamental to making health care work for PWH. Support services for PWH are not covered in any comprehensive way by Medicaid or other public insurance initiatives that have been expanded by the Affordable Care Act. As the HIV epidemic in the United States increasingly impacts low-income individuals, support services help stabilize individuals living with or at risk of HIV. When needs are met, and life's emergencies are held at bay, PWH are poised to remain connected to care and treatment.

3.) Access to FNS and the Triple Aim

Access to appropriate food and nutrition services (FNS) are increasingly recognized as key to accomplishing the triple aim of national healthcare reform for PWH.

Better Health Outcomes

When clients get effective FNS and become food secure, they then keep scheduled primary care visits, score higher on health functioning, are at lower risk for inpatient hospital stays and are more likely to take their medicines[i]. Studies show both the health benefits of access to MNT and/or nutrition counseling for people with HIV infections[ii] and the resulting decreases in their healthcare costs. Compare these outcomes to PWH who are food insecure, who have:

- Lower CD4 counts & lower likelihoods of having undetectable viral loads[iii]
- More ER visits[iv] & increased morbidity and mortality[v]
- More missed primary care appointments & reduced use of antiretroviral therapy[vi].

Lower Healthcare Costs

Millions of dollars in healthcare expenditures are saved through the provision of FNS to PWH. A recent study comparing participants in a medically-tailored FNS program vs. a control group within a local managed care organization found that average monthly healthcare costs for PWH fell 80% in first three months after receiving FNS[vii]. If hospitalized, nourished clients' costs were 30% lower, their hospital length of stay was cut by 37% and they were 20% more likely to be able to be discharged to their homes rather than a more expensive institution[viii]. Furthermore, FNS are a very inexpensive intervention. For each day in a hospital saved, you can feed a person a medically-tailored diet for half a year.

Improved Patient Satisfaction

Studies show nutrition counseling improves quality of life[ix]. Members overwhelmingly report that our services help them live more independently, eat more nutritiously and manage their medical treatment more effectively.

4.) FNS and the National HIV/AIDS Strategy (NHAS)

Access to FNS for PWH is fundamental to fulfilling the goals of the NHAS.

- **NHAS Goal: Reducing new HIV infections:** PWH who are food insecure are less likely to have undetectable viral loads in a statistically significant way. Undetectable viral loads prevent transmission 96% of the time[x], thus, FNS is key to prevention[xi].
- **NHAS Goal: Increasing access to care and improving health outcomes for people living with HIV:** PWH who receive effective FNS are more likely to keep scheduled primary care visits, score higher on health functioning, are at lower risk for inpatient hospital stays and are more likely to take their medicines[xii].
- **NHAS Goal: Reducing HIV-related disparities and health inequities:** By providing FNS to PWH who are in need largely because of poverty, we improve health outcomes, thereby reducing health disparities[xiii].
- **NHAS Goal: Achieving a more coordinated national response to the HIV epidemic:** There remains a tremendous variation by state in coverage of food and nutrition services both inside and outside of Ryan White, making support for Ryan White HIV Program all the more needed. Ultimately, if we are going to achieve a more coordinated national response to the HIV epidemic and our quest to reduce healthcare spending nationwide, FNS must be included in all healthcare reform efforts, including Ryan White and the ACA.

Conclusion

We are deeply aware of the difficult decisions that face the members of the Committee in the current fiscal environment. Yet, research shows that investment in FNS, with the great return in prevention and retention in HIV care, are vital to lowering the number of new infections in the domestic HIV epidemic and ultimately reducing healthcare costs and preserving healthcare resources for the future. A client's diet can literally have life and death consequences. When people are severely ill, good nutrition is one of the first things to deteriorate, making recovery and stabilization that much harder, if not impossible. Early and reliable access to medically-appropriate FNS helps PWH live healthy and productive lives, produces better overall health outcomes and reduces health care costs.

Along with our colleagues, we appreciate the opportunity to offer this testimony regarding the FY 2017 Appropriations process. We are also pleased to offer our assistance and expertise, including information from our Research Library.

Thank you.

Karen Pearl
President & CEO
God's Love We Deliver
166 Avenue of the Americas
New York, NY 10013
212-294-8171

[i] Aidala A, Yomogida M, Vardy Y & the Food & Nutrition Study Team. Food and Nutrition Services, HIV Medical Care, and Health Outcomes. New York State Department of Health: Resources for Ending the Epidemic, 2014. Available at https://www.health.ny.gov/diseases/aids/ending_the_epidemic/docs/key_resources/housing_and_supportive_services/chain_factsheet3.pdf

[ii] Academy of Nutrition and Dietetics (formerly American Dietetic Association). HIV/AIDS Nutrition Evidence Analysis Project at http://www.adaevidencelibrary.com/conclusion.cfm?conclusion_statement_id=250707 Accessed 29 July 2012.

[iii] Aidala A., Yomogida M., and the HIV Food & Nutrition Study Team (2011);
Singe AW,Weiser SD, McCoy, SI. Does Food Insecurity Undermine Adherence to Antiretroviral Therapy? A Systematic Review. AIDS Behav (2015) 19:1510–1526.

[iv] Ibid.

[v] Anema A, Chan K, Yip B, Weiser S, Montaner JSG, Hogg RS. Impact of food insecurity on survival among HIV-positive injection drug users receiving antiretroviral therapy in a Canadian cohort. 141st APHA Annual Meeting, Nov. 2-6, 2013. Boston, MA. Abstract #: 290277

[vi] Aidala A., Yomogida M., and the HIV Food & Nutrition Study Team (2011).

[vii] Gurvey J, Rand K, Daugherty S, Dinger C, Schmeling J, Laverty N. Examining Health Care Costs Among MANNA Clients and a Comparison Group. J Prim Care Community Health. (2013) 4:311-317

[viii] Ibid.

[ix] Rabeneck L, Palmer A, Knowles JB, Seidehamel RJ, Harris CL, Merkel KL, Risser JMH, Akrabawi SS. A randomized controlled trial evaluating nutrition counseling with or without oral supplementation in malnourished HIV-infected patients. J Am Diet Assoc. (1998) 98: 434-438;Schwenk A, Steuck H, Kremer G. Oral supplements as adjunctive treatment to nutritional counseling in malnourished HIV-infected patients: randomized controlled trial. Clinical Nutrition (1999) 18(6): 371-374.

[x] M. S. Cohen *et al.*, Prevention of HIV-1 Infection with Early Antiretroviral Therapy. N. Engl. J. Med.(2011) 365, 493-505 . HPTN 052

[xi] Palar K, Laraia B, Tsai A, Weiser SD Food insecurity is associated with sexually transmitted infections and HIV serostatus among low income adults in the National Health and Nutrition Examination Survey (NHANES) (1999-2010). Presented at the American Public Health Association 141st Annual Meeting, Boston, MA, November 5, 2013.

[xii] Aidala A, Yomogida M, Vardy Y & the Food & Nutrition Study Team. Food and Nutrition Services, HIV Medical Care, and Health Outcomes. New York State Department of Health: Resources for Ending the Epidemic, 2014. Available at

xiii Weiser SD, Frongillo EA, Ragland K, Hogg RS, Riley ED, Bangsberg DR. Food insecurity is associated with incomplete HIV RNA suppression among homeless and marginally housed HIV-infected individuals in San Francisco. J Gen Intern Med. (2009) 24(1):14-20.

Testimony of the Health Professions and Nursing Education Coalition (HPNEC) Concerning HRSA's Title VII & Title VIII Health Professions Programs

Submitted for the Record to the House Appropriations Subcommittee on Labor, Health and Human Services, Education, and Related Agencies – April 15, 2016

The members of the Health Professions and Nursing Education Coalition (HPNEC) are pleased to submit this statement for the record recommending $524 million in fiscal year (FY) 2017 for the health professions education and training programs authorized under Titles VII and VIII of the Public Health Service Act and administered through the Health Resources and Services Administration (HRSA). Additionally, because HRSA has been administering the Behavioral Health Workforce Education and Training (BHWET) Program, we also support the President's FY 2017 budget proposal of shifting funds previously appropriated to the Substance Abuse and Mental Health Services Administration to HRSA.

HPNEC is an alliance of national organizations dedicated to ensuring the health care workforce is trained to meet the needs of the country's growing, aging, and diverse population. Titles VII and VIII are the only federally-funded programs that seek to improve the supply, distribution, and diversity of the health professions workforce, with a focus on primary care and interdisciplinary training. By providing educational and training opportunities to aspiring and practicing health professionals, the programs also play a critical role in helping the workforce adapt to meet the nation's changing health care needs.

Titles VII and VIII are structured to allow grantees to test educational innovations, respond to changing delivery systems and models of care, and address timely topics in their communities. By assessing the needs of the communities they serve, Titles VII and VIII are well positioned to fill gaps in the workforce and increase access to care for all populations. Further, the programs emphasize interprofessional education and training, bringing together knowledge and skills across disciplines to provide effective, efficient and coordinated care.

HPNEC recognizes the Subcommittee faces difficult decisions in a constrained budget environment; therefore, we are grateful the Subcommittee recognized that these programs are a high priority and continued its commitment to programs supporting health care workforce development in the FY 2016 omnibus spending package. The nation faces a shortage of health professionals, which will be exacerbated by increasing demand for health care services. Failure to fully fund the Title VII and Title VIII programs would jeopardize activities to fill these vacancies and to prepare the next generation of health professionals.

The Title VII and Title VIII programs can be considered in seven general categories:

- The **Primary Care Medicine and Oral Health Training** programs support education and training of primary care professionals to improve access and quality of health care in underserved areas. According to HRSA, approximately 20 percent of Americans live in rural or urban areas designated as health professional shortage areas (HPSA). The primary care medical and oral health training grants are also used to develop curricula and test training methods to transform health care practice and delivery, including innovations in the primary care team's management of chronic disease, patient-centered models of care, and transitioning across health care settings. The *General Pediatrics*, *General Internal Medicine*, and *Family Medicine* programs

provide critical funding for primary care physician training in community-based settings and support a range of initiatives, including medical student and residency training, faculty development, and the development of academic administrative units. The *Rural Physician Training Grants* focus on increasing the number of medical school graduates practicing in rural communities. The primary care cluster also provides grants for *Physician Assistant* programs to encourage and prepare students for primary care practice in rural and urban Health Professional Shortage Areas. The *General Dentistry, Pediatric Dentistry, Dental Public Health, and Dental Hygiene programs* provide grants to dental schools, dental hygiene schools, and hospitals to create or expand primary care dental training.

- Because much of the nation's health care is delivered in remote areas, the **Interdisciplinary, Community-Based Linkages** cluster supports community-based training of health professionals. These programs are designed to encourage health professionals to return to such settings after completing their training and to encourage collaboration between two or more disciplines. The *Clinical Training in Interprofessional Practice* program supports interdisciplinary training opportunities that prepare providers to deliver coordinated, efficient, and high-quality care. The *Area Health Education Centers (AHECs)* offer clinical training opportunities to health professions and nursing students in rural and other underserved communities by extending the resources of academic health centers to these areas. AHECs improve health by leading the nation in the recruitment, training, and retention of a diverse health workforce for underserved communities. By leveraging state and local matching funds to form networks of health-related institutions, AHECs also provide education services to students, faculty, and practitioners. The final FY 2016 omnibus spending package combined the Title VIII *Comprehensive Geriatric Education* program, which establishes traineeships for individuals who are preparing for advanced education in geriatric nursing, with the Title VII geriatrics programs, including the *Geriatrics Education Centers* programs, which support interprofessional geriatrics education and training for geriatrics specialists and non-specialists, *Geriatric Training for Physicians, Dentists, and Behavioral/Mental Health Professionals* programs, which increase the supply of geriatrics faculty and re-train faculty in geriatrics, and the *Geriatric Academic Career Awards* (GACA) program, which promote the development of academic clinician educators who provide clinical training in geriatrics. Individually, these programs are all designed to bolster the number and quality of health care providers caring for the rapidly growing number of older adults and to expand geriatrics training to all health care professionals. The newly combined program—the *Geriatrics Workforce Enhancement* program (GWEP)—seeks to improve integration of geriatrics with primary care across health settings and disciplines. However, due to the nature of the program consolidation, it is not yet clear if or how all of the previous activities will be supported in the new program. Specifically, we are concerned that the GACAs may not continue to play their important role in the new GWEP structure. The *Graduate Psychology Education* (GPE) program is the nation's only federal program dedicated solely to the education and training of doctoral-level psychologists. GPE supports the interprofessional training of doctoral-level psychology students in providing supervised mental and behavioral health services to underserved populations (i.e. older adults, children, chronically ill, and victims of

abuse and trauma, including returning military personnel and their families) in rural and urban communities. The *Mental and Behavioral Health Education and Training Grant Program* supports the training of psychologists, social workers, and child and adolescent professionals. These programs together work to close the gap in access to quality mental and behavioral health care services by increasing the number of qualified mental health clinicians.

- The **Minority and Disadvantaged Health Professionals Training** cluster helps improve health care access in underserved areas and the representation of minority and disadvantaged individuals in the health professions. Diversifying the health care workforce is a central focus of the programs, making them a key player in mitigating racial, ethnic, and socio-economic health disparities. Further, the programs emphasize cultural competency for all health professionals, an important role as the nation's population is growing and becoming increasingly diverse. *Minority Centers of Excellence* support increased research on minority health, establish educational pipelines, and provide clinical experiences in community-based health facilities. The *Health Careers Opportunity Program* helps to improve the development of a competitive applicant pool through partnerships with local educational and community organizations and extends the health careers pipeline to the K-12 level. The *Faculty Loan Repayment and Faculty Fellowship* programs provide incentives for schools to recruit underrepresented minority faculty. The *Scholarships for Disadvantaged Students* supports students from disadvantaged backgrounds who are eligible and enrolled as full-time health professions students.

- The **Health Professions Workforce Information and Analysis** program provides grants to institutions to collect and analyze data to advise future decision-making on the health professions and nursing programs. The *Health Professions Research and Health Professions Data* programs have developed valuable, policy-relevant studies on the distribution and training of health professionals. The *National Center for Workforce Analysis* performs research and analysis on health workforce issues, including supply and demand, to help inform both public and private decision-making.

- The **Public Health Workforce Development** programs help increase the number of individuals trained in public health, identify the causes of health problems, and respond to such issues as managed care, new disease strains, food supply, and bioterrorism. The *Public Health Traineeships and Public Health Training Centers* seek to alleviate the critical shortage of public health professionals by providing up-to-date training for current and future public health workers, particularly in underserved areas. *Preventive Medicine Residencies*, which do not receive funding through Medicare GME, provide training in the only medical specialty that teaches both clinical and population medicine to improve community health. This cluster also includes a focus on loan repayment as an incentive for health professionals to practice in disciplines and settings experiencing shortages. The *Pediatric Subspecialty Loan Repayment Program* offers loan repayment for pediatric medical subspecialists, pediatric surgical specialists, and child and adolescent mental and behavioral health specialists, in exchange for service in underserved areas.

- The **Nursing Workforce Development** programs under Title VIII provide support for nurses and nursing students across the entire education spectrum improve the access to, and quality of, health care in underserved areas. These programs provide the largest source of federal funding for nursing education, providing loans, scholarships, traineeships, and programmatic support that supports nurses and nursing students as well as numerous academic nursing institutions and health care facilities. At the same time, the need for high-quality nursing services is expected to grow, particularly in rural and underserved areas. The *Advanced Nursing Education* program awards grants to train a variety of nurses with advanced education, including clinical nurse specialists, nurse practitioners, certified nurse-midwives, certified registered nurse anesthetists, public health nurses, nurse educators, and nurse administrators. *Nursing Workforce Diversity* grants help to recruit and retain students from minority and disadvantaged backgrounds to the nursing profession through scholarships, stipends, and other retention activities. Graduate nursing students are provided reimbursement for tuition and program costs through the *Advanced Education Nursing Traineeships and Nurse Anesthetist Traineeships*. The *Nurse Education, Practice, Quality, and Retention* program helps schools of nursing, academic health centers, nurse-managed health centers, state and local governments, and other health care facilities to develop programs that provide nursing education, promote best practices, and enhance nurse retention. The *Loan Repayment and Scholarship Program* repays up to 85 percent of nursing student loans and offers full-time and part-time nursing students the opportunity to apply for scholarship funds in exchange for two years of practice in a designated critical shortage facility. The *Comprehensive Geriatric Education* grants support the education of registered nurses and nursing professionals who will provide direct care to older Americans, develop and disseminate geriatric curricula, train faculty members, and provide continuing education. The *Nurse Faculty Loan* program supports graduate students pursing the opportunity to become nursing faculty members through loan repayment in exchange for service as nursing faculty.

- The loan programs under **Student Financial Assistance** support financially disadvantaged health professions students. The *NURSE Corps* supports undergraduate and graduate nursing students with a preference for those with the greatest financial need. The *Primary Care Loan* (PCL) program provides loans in return for dedicated service in primary care. The *Health Professional Student Loan* (HPSL) program provides loans for financially needy health professions students based on institutional determination. These programs are funded out of each institution's revolving fund and do not receive federal appropriations. The *Loans for Disadvantaged Students* program provides grants to institutions to make loans to disadvantaged students.

Title VII and Title VIII programs guide individuals to high-demand health professions jobs, helping individuals reach their goals and communities fill their health needs. Further, numerous studies demonstrate that the Title VII and Title VIII programs graduate more minority and disadvantaged students and prepare providers that are more likely to serve in Community Health Centers (CHC) and the National Health Service Corps (NHSC).

The multi-year nature of health professions education and training, coupled with provider shortages across many disciplines and in many communities, necessitate a strong, continued, and reliable commitment to the Title VII and Title VIII programs.

While HPNEC members understand the budget limitations facing the Subcommittee, we respectfully urge support for $524 million for the Title VII and VIII programs in FY 2017, and providing BHWET funding directly to HRSA. We look forward to working with the Subcommittee to prioritize the health professions programs in FY 2017 and into the future.

March 10, 2016

The Honorable Hal Rogers
Chairman
Committee on Appropriations
H-307 The Capitol
Washington, DC 20515

The Honorable Nita Lowey
Ranking Member
Committee on Appropriations
1016 Longworth House Office Building
Washington, DC 20515

The Honorable Tom Cole
Chairman
Committee on Appropriations
Subcommittee on Labor, HHS & Education
2358-B Rayburn House Office Building
Washington, DC 20515

The Honorable Rosa DeLauro
Ranking Member
Committee on Appropriations
Subcommittee on Labor, HHS & Education
1016 Longworth House Office Building
Washington, DC 20515

Dear Chairmen Rogers and Cole and Ranking Members Lowey and DeLauro:

We thank Congress for recognizing and responding decisively in Fiscal Year 2016 to the challenges of Alzheimer's disease and related dementias (including vascular, Lewy body and frontotemporal dementia). We applaud your determination to seize the enormous opportunities for America if we invest in the science, care and support required to overcome these challenges and for recognizing the consequences if we fail to act. Doing so is a national priority, an economic and budgetary necessity, a health and moral imperative.

We urge that you build upon recent developments and include the resources necessary to support dementia and aging research within the FY 2017 budget. Specifically, we urge you to move with all alacrity to commit at least 1 percent of the cost of treating persons living with dementia to research supported by the National Institutes of Health (NIH) and to move us substantially closer to this goal in FY 2017. Today, this amount would be approximately $2 billion, the minimum annual amount of public research funding leading dementia researchers have recommended must be committed to maximize the likelihood of achieving the nation's goal of preventing and effectively treating dementia by 2025.

As you assemble the FY 2017 Labor, Health and Human Services, Education and Related Agencies Appropriations Act, we urge that you include:

- **A minimum increase of $400 million in Alzheimer's disease and related dementias research at the NIH over the FY 16 enacted level.** Such an increase would result in an NIH-wide dementia research budget of about $1.336 billion in FY 2017. If similar commitments are made over the following two years, we will meet and exceed the $2 billion target by FY 2019.

- **A minimum increase of $500 million over the FY 2016 enacted level for aging research across the NIH, in addition to the funding for dementia.** This increase will

ensure that the NIH and NIA have the resources they need, not only to address dementia, but also the many other age-related chronic diseases.

- **A minimum increase of $25 million in the budgets for dementia care and services programs over the FY 2016 enacted levels** at the Administration for Community Living, Health Resources and Services Administration, the Centers for Disease Control and Prevention, and the Department of Justice.

There are few more compelling or complex issues to confront our aging society than dementia, now and over the coming decades. These conditions impose enormous costs to our nation's health and prosperity, costs that are skyrocketing.[i] Due to NIA's Health and Retirement Study (HRS), we now know that the health care costs of caring for people with dementia in the United States are comparable to, if not greater than, those for heart disease and cancer.[ii] A recent analysis of HRS data revealed that, in the last five years of life, total health care spending for people with dementia was more than a quarter-million dollars per person, some 57 percent greater than costs associated with death from other diseases, including cancer and heart disease.[iii] Today, more than five million Americans[iv] have dementia at an annual cost to our economy exceeding $200 billion.[v] Alzheimer's disease contributes to the deaths of approximately 500,000 Americans each year, making it the third leading cause of death in the United States.[vi] If the current trajectory persists, at least 13 million Americans will have dementia in 2050 and total costs of care are projected to exceed (inflation adjusted 2014 dollars) $1 trillion annually.[vii] The federal government, through Medicare and Medicaid payments, shoulders an estimated 70 percent of all such direct care costs.

The choice before our nation is not whether to pay for dementia -- we are paying dearly. The question is whether we will emulate the investment strategies that have led to remarkable progress in fighting other leading causes of death such as cancer, HIV/AIDS and heart disease and achieve similar breakthroughs, or spend trillions to care for tens of millions of people. A modernized and more robust research portfolio can help America prevent this catastrophe and move us closer to achieving our national goal of preventing and effectively treating dementia by 2025.[viii]

Due to leadership and direction from Congress, HHS continues to increase prioritization of Alzheimer's disease and related dementias. The publicly appointed members of the Advisory Council on Alzheimer's Research, Care, and Services have generated their most thoughtful and catalytic recommendations for the annual update to the National Plan to Address Alzheimer's Disease. There is heightened focus on improving care for people with advanced dementia.[ix] The Food and Drug Administration is encouraging new research avenues and clarifying regulatory approval pathways. Your committee and NIH have moved mountains to create additional resources, public-private partnerships, and a culture of urgency. Across the NIH, institutes are supporting promising Alzheimer's disease and related dementias research to: understand genetic risk factors;[x] address health disparities among women,[xi] African Americans,[xii] Hispanics,[xiii] and persons with intellectual disabilities;[xiv] and pursue cutting-edge trials aimed at preventing or substantially slowing disease progression by administering treatments much earlier in the disease process.[xv] In FY 2017, the NIA plans to increase its research focus on dementia epidemiology, health disparities, and caregiving.[xvi]

As urgently as resources are needed to enable scientific breakthroughs, millions of Americans already living with dementia deserve equal commitments to programs to protect and enhance their quality of life. New funding is essential to sustain core Older Americans Act services and develop and disseminate evidence-based services instrumental to achieving the national plan's goals to enhance care quality, efficiency and expand supports.[xvii] These programs provide

needed respite to family caregivers and training in best practices to meet the many challenges of providing care to persons with dementia. Until an effective prevention, disease-modifying treatment or cure comes to market, families rely on these programs to protect their own well-being while helping their loved ones remain independent, in the community while delaying placement in institutional settings.

Thank you for considering our views and for your commitment to overcoming Alzheimer's disease and related dementias. Please contact Ian Kremer, executive director of Leaders Engaged on Alzheimer's Disease (the LEAD Coalition),[xviii] ikremer@leadcoalition.org or (571) 383-9916, with questions or for additional information.

Sincerely,

Abe's Garden

ACT on Alzheimer's

ActivistsAgainstAlzheimer's

African American Network Against Alzheimer's

Ageless Alliance

AgeneBio

Aging and Memory Disorder Programs, Howard University

Allergan

Alliance for Aging Research

Alliance for Patient Access

Alzheimer's & Dementia Alliance of Wisconsin

Alzheimer's Drug Discovery Foundation

Alzheimer's Greater Los Angeles

Alzheimers North Carolina

Alzheimer's Orange County

Alzheimer's Tennessee

AMDA – The Society for Post-Acute and Long-Term Care Medicine

American Academy of Neurology

American Association for Long Term Care Nursing

American Association of Nurse Assessment Coordination

American Federation for Aging Research (AFAR)

American Geriatrics Society

ARGENTUM | Expanding Senior Living

Association of Population Centers

Laura D. Baker, PhD (Wake Forest School of Medicine*)

Banner Alzheimer's Institute

David M. Bass, PhD (Benjamin Rose Institute on Aging*)

Beating Alzheimer's by Embracing Science

Benjamin Rose Institute on Aging

Biogen Idec

Soo Borson MD (University of Washington Schools of Medicine and Nursing*)

James Brewer, M.D., Ph.D. (UC San Diego and Alzheimer's Disease Cooperative Study*)

BrightFocus Alzheimer's Disease Research

Christopher M. Callahan, MD (Indiana University Center for Aging Research*)

Caregiver Action Network

CaringKind

Center for Alzheimer Research and Treatment, Harvard Medical School

Center for BrainHealth at The University of Texas at Dallas

Center for Elder Care and Advanced Illness, Altarum Institute

Sandra Bond Chapman, PhD (Center for BrainHealth at The University of Texas at Dallas*)

ClergyAgainstAlzheimer's

Cleveland Clinic Foundation

CorTechs Labs

Jeffrey Cummings, MD, ScD (Cleveland Clinic Lou Ruvo Center for Brain Health*)

Cure Alzheimer's Fund

CurePSP

Darrell K. Royal Fund for Alzheimer's Research

Dementia Friendly America

Department of Neurology, Washington University School of Medicine

Rachelle S. Doody, MD, PhD (Baylor College of Medicine*)

Gary Epstein-Lubow, MD (Alpert Medical School of Brown University*)

Fujirebio

Sam Gandy, MD, PhD (Icahn School of Medicine at Mount Sinai*)

Joseph E. Gaugler, Ph.D. (School of Nursing, Center on Aging, University of Minnesota*)

General Electric Healthcare

Daniel R. George, Ph.D, M.Sc (Penn State College of Medicine*)

Georgetown University Medical Center Memory Disorders Program

Gerontological Society of America

Laura N. Gitlin, PhD (Johns Hopkins School of Medicine*)

Global Coalition on Aging

Lisa P. Gwyther, MSW, LCSW (Duke University Medical Center*)

David Holtzman, MD (Washington University School of Medicine, Department of Neurology*)

Home Instead Senior Care

Huffington Center on Aging

Indiana University Center for Aging Research

Janssen R&D

Kathy Jedrziewski, PhD (University of Pennsylvania*)

Katherine S. Judge, PhD (Cleveland State University*)

Keep Memory Alive

Diana R Kerwin, MD (Texas Alzheimer's and Memory Disorders*)

Walter A. Kukull, PhD (School of Public Health, University of Washington*)

LatinosAgainstAlzheimer's

Latino Alzheimer's and Memory Disorders Alliance

Lewy Body Dementia Association

LuMind Research Down Syndrome Foundation

Lundbeck

Mary Mittelman, DrPH (New York University Medical Center*)

David G. Morgan, PhD (USF Health Byrd Alzheimer's Institute*)

Mount Sinai Center for Cognitive Health

National Alliance for Caregiving

National Asian Pacific Center on Aging

National Association of Nutrition and Aging Services Programs

National Certification Council for Activity Professionals

National Committee to Preserve Social Security and Medicare

National Council for Behavioral Health

National Down Syndrome Society

National Hispanic Council On Aging (NHCOA)

National Task Group on Intellectual Disabilities and Dementia Practices

Neurotechnology Industry Organization

New York Academy of Sciences

NFL Neurological Center

NYU Alzheimer's Disease Center

NYU Langone Center on Cognitive Neurology

Thomas O. Obisesan, MD, MPH (Howard University Hospital*)

OWL-The Voice of Women 40+

Patient Engagement Program, a subsidiary of CurePSP

Pat Summitt Foundation

Piramal Imaging S.A.

Planetree

Population Association of America

Prevent Alzheimer's Disease 2020

Eric Reiman, MD (Banner Alzheimer's Institute*)

Research!America

ResearchersAgainstAlzheimer's

Stephen Salloway, M.D., M.S. (The Warren Alpert Medical School of Brown University*)

Second Wind Dreams, Inc./ Virtual Dementia Tour

Reisa A. Sperling, MD, MMSc (Center for Alzheimer Research and Treatment, Harvard Medical School*)

Rudolph Tanzi, PhD (Department of Neurology, MGH/Harvard Medical School*)

The Association for Frontotemporal Degeneration

The Evangelical Lutheran Good Samaritan Society

The Youth Movement Against Alzheimer's

Geoffrey Tremont, Ph.D., ABPP-CN (Alpert Medical School of Brown University*)

R. Scott Turner, MD, PhD (Georgetown University Memory Disorders Program*)

UsAgainstAlzheimer's, LEAD Coalition co-convener

USF Health Byrd Alzheimer's Institute

Volunteers of America, LEAD Coalition co-convener

Nancy Wilson, MA LCSW (Baylor College of Medicine*)

WomenAgainstAlzheimer's

** Affiliations of individual researchers are for identification purposes only and do not necessarily represent the endorsement of the affiliated institution.*

Ann Cooper, Chair
Robert Blancato, Executive Director
National Association of Nutrition and Aging Services Programs (NANASP)

Chairman Cole, Ranking Member DeLauro;

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 Department of Health and Human Services' proposed increase of $13.8 million for Older Americans Act Title III(C) senior nutrition programs within the Administration for Community Living, and in support of, at a minimum, the President's request for level funding for the Senior Community Service Employment Program within the Department of Labor.

Older Americans Act Title III(C) Senior Nutrition Programs

Older Americans Act congregate and home-delivered meals programs are provided in every state and congressional district in this nation. Approximately 2.4 million seniors in 2014 received these services. Studies have found that 50 percent of all persons age 85 and over need help with instrumental activities of daily living, including obtaining and preparing food. Older Americans Act nutrition programs address these concerns. Thus, these meal recipients are able to remain independent in their homes and communities and are not forced into hospitals or nursing homes due to an inability to maintain a proper diet.

In addition, for participants in the congregate program, the nutrition programs provide a daily opportunity for socialization, preventing isolation and promoting health and wellness. For home-delivered meals recipients, their delivery driver may be the only person they see all day—therefore, this wellness check is also key to their health.

In FY 2016, Older Americans Act Title III(C) programs received appropriations in the amount of $835 million. Though we are thankful that this represents an increase from FY 2015, unfortunately, this does not keep pace with the rising cost of food, inflation, and the growing numbers of older adults. In fact, year over year, the number of older adults receiving meals is shrinking even as the need is growing.

The additional $13.8 million in funding for congregate and home-delivered meals will help to counteract inflation and provide more than 1.3 million additional meals. This does not keep up with the growing demand for services, but it would at least prevent further reductions in services. As we saw in FY 2013 when sequestration was in effect, our programs had lengthy wait lists and some sites even closed for lack of funding. One NANASP program created its first wait list in over 90 years of operation.

Investing in these programs is cost-effective because many common chronic conditions such as hypertension, heart disease, diabetes, and osteoporosis can be effectively prevented and treated with proper nutrition. The Academy of Nutrition and Dietetics estimates that 87 percent of older

adults have or are at risk of hypertension, high cholesterol, diabetes, or some combination of all of these. These seniors need healthy meals, access to lifestyle programs, and nutrition education and counseling to avoid serious medical care.

Older adults who are not receiving proper meals can also become malnourished and undernourished. This makes it harder for them to recover from surgery and disease, makes it more difficult for their wounds to heal, increases their risk for infections and falls, and decreases their strength that they need to take care of themselves. Malnourished older adults are more likely to have poor health outcomes and to be readmitted to the hospital—their health costs can be 300 percent greater than those who are not malnourished on entry to the health care system.

Access to Older Americans Act meals is essential to keeping these older adults out of costly nursing facilities and hospitals. On average, a senior can be fed for a year for about $1,300. The cost of feeding a senior for a year is approximately the same as the cost of one day's stay in a hospital or less than the cost of 10 days in a nursing home. The cost savings to Medicare and Medicaid that this creates cannot be over-emphasized. One study estimates that for every dollar invested in the Older Americans Act nutrition programs, Medicaid saves $50.

Further, these services are designed to target those in the "greatest social and economic need," according to the Older Americans Act and to actual practice in the field. According to ACL's studies, approximately two-thirds of home-delivered meal recipients have annual incomes of $20,000 or less. Sixty-two percent of these recipients report that these meals represent at least half their food intake each day. And yet, the Government Accountability Office found that only about nine percent of low-income older adults are even receiving meals services. For a small investment, more at-risk older adults could receive nutritious meals.

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. SCSEP is the only federal program targeted to serve specifically 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.

SCSEP currently provides jobs for about 67,000 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. The average age of a program participant is 62; according to the Department of Labor, 65% of all SCSEP participants in Program Year 2012 were women, 46% were minorities, and 88% were at or below the federal poverty level.

NANASP has one SCSEP national grantee and approximately 80 SCSEP state and local sub-grantees who are NANASP members, as well as many nutrition providers among our membership who have SCSEP employees on staff.

SCSEP, as authorized by Title V of the Older Americans Act (OAA), has a dual purpose: "to foster individual economic self-sufficiency and to increase the number of participants placed in unsubsidized employment in the public and private sectors, while maintaining the community service focus of the program."

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.

Considering that other programs that received cuts during the FY 2013 sequestration have not had their funding even partially restored, we are pleased that in FY 2016, funding for SCSEP held level at $434.4 million where it has remained since its partial restoration in FY 2014. However, this is not enough to meet the growing need for SCSEP—both in participants and in wages.

Many states and localities are raising the minimum wage, and this dilutes SCSEP funding, which has to increase to match increasing wages. This decreases the number of participants SCSEP can handle, yet the older population is growing. The last time there was an increase in funding for SCSEP, other than under the FYs 2009-2010 stimulus package, was when the federal minimum wage was increased. Though wages have not increased at the federal level, they have increased in enough states and localities to the point that SCSEP is becoming strained.

With more than 10,000 seniors turning 65 every day, now is the time to provide an even greater investment in these proven and cost-effective programs for older adults.

Thank you for your past and future support.

Alpha-1 Foundation
Labor-Health and Human Services-Education Appropriations Subcommittee
National Institutes of Health

On behalf of the Alpha-1 Foundation, I am pleased to submit testimony in support of funding for the National Institutes of Health (NIH). We urge you to include $34.5 billion for NIH in the Labor-Health and Human Services-Education appropriations bill for FY2017.

The Alpha-1 Foundation is committed to finding a cure for Alpha-1 Antitrypsin Deficiency (Alpha-1) and to improving the lives of people affected by Alpha-1 worldwide. This condition is inherited and may result in serious lung disease, like COPD, and/or liver disease. Like many other inherited conditions, those with Alpha-1 must have two defective genes to cause disease. In the case of Alpha-1 this results in lower than normal levels of protective protein in the blood and lungs.

Prioritizing research related to Alpha-1, specifically, Alpha-1 associated Chronic Obstructive Pulmonary Disease (COPD) at the National Heart Lung and Blood Institute (NHLBI) in FY2017 is essential to tackling the broader issue of not just rare diseases, but also public health issues related to COPD. In FY2016, the NHLBI convened an interagency meeting on federal COPD planning. Unfortunately we have yet to see any peer-reviewed publications following this meeting. I hope that you will include language in the accompanying report that urges NHLBI to move forward on efforts to address the rising burden of COPD in the U.S.

Specifically, we know that Alpha 1 Antitrypsin Deficiency (Alpha 1) is a major genetic risk factor for developing COPD. Therefore we at the Alpha-1 Foundation believe that a treatment algorithm for Alpha-1 related disease along with a coordinated public-private collaborative approach will not only increase the knowledge that can improve the diagnosis of Alpha 1, but make for a more clear understanding of COPD. We urge you to encourage the NHLBI to convene a group of expert stakeholders and other federal agencies to take the first steps in developing such a treatment algorithm.

In short, we are committed to ensuring that Alphas have a community of support, places to go for answers, and in furthering research for therapies and ultimately, cures. Prioritizing research at the NHLBI, specifically ensuring that this treatment algorithm related to Alpha-1 associated COPD is created, will go a long way in furthering these goals.

Centers for Disease Control and Prevention (CDC) Coalition

C/o American Public Health Association 800 I Street NW Washington, DC, 20001 202-777-2514

Donald Hoppert, Director of Government Relations, American Public Health Association
Testimony submitted for the record on April 15, 2016
House Appropriations Subcommittee on Labor,
Health and Human Services, Education and Related Agencies

The CDC Coalition is a nonpartisan coalition of more than 140 organizations committed to strengthening our nation's prevention programs. We represent millions of public health workers, clinicians, researchers, educators and citizens served by CDC programs.

We believe Congress should support CDC as an agency, not just its individual programs and urge a funding level of **$7.8 billion for CDC's programs in FY 2017**. We are disappointed President Obama's budget request would cut CDC's program level by $194 million below FY 2016. We acknowledge that the president's budget provides increased funding for several important programs and initiatives such as combating antibiotic resistance and preventing prescription drug overdose. We are also pleased that the president's budget would fully allocate the Prevention and Public Health Fund for public health activities. Unfortunately, the president's budget cuts or completely eliminates other important programs including the REACH program, the Preventive Health and Health Services Block Grant, cancer prevention and control, immunizations and environmental health tracking and we urge you to restore the funding.

CDC is a key source of funding and technical assistance for state and local programs that aim to improve the health of communities. CDC funding provides the foundation for state and local public health departments, supporting a trained workforce, laboratory capacity and public health education communications systems.

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 last year's multi-state measles outbreak to pandemic flu preparedness, CDC is the nation's – and the world's – expert resource and response center, coordinating communications and action and serving as the laboratory reference center for identifying, testing and characterizing potential agents of biological, chemical and radiological terrorism, emerging infectious diseases and other public health emergencies. CDC serves as the lead agency for bioterrorism and public health emergency preparedness and must receive sustained support for its preparedness programs to meet future challenges. We urge you to provide adequate funding for CDC's infectious disease, laboratory and emergency preparedness and response activities.

Heart disease is the nation's No. 1 cause of death. In 2014, over 614,000 people in the U.S. died from heart disease, accounting for nearly 23 percent of all U.S. deaths. More males than females died of heart disease in 2014, 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 2014, nearly 133,000 people died of stroke, accounting for about one of every 20 deaths. CDC's Heart Disease and Stroke Prevention Program, WISEWOMAN, and Million Hearts work to improve cardiovascular health.

Cancer is the second most common cause of death in the U.S. More than1.6 million new cancer cases and 595,690 deaths from cancer are expected in 2016. In 2013 the direct medical costs of cancer were $74.8 billion. The National Breast and Cervical Cancer Early Detection Program helps millions of low-income, uninsured and medically underserved women gain access to lifesaving breast and cervical cancer screenings and provides a gateway to treatment upon diagnosis. CDC also funds grants to all 50 states to develop comprehensive cancer control plans, bringing together a broad partnership of public and private stakeholders to set joint priorities and

implement specific cancer prevention and control activities customized 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 that help to prevent tobacco addiction and provide resources to encourage smokers to quit. We must continue to support these vital programs to reduce the enormous health and economic costs of tobacco use in the U.S.

Of the 29.1 million Americans who have diabetes, more than 8 million cases are undiagnosed. Each year, about 1.4 million people are newly diagnosed with diabetes. Diabetes is the leading cause of kidney failure, nontraumatic lower-limb amputations, and new cases of blindness among adults in the U.S. The total direct and indirect costs associated with diabetes were $245 billion in 2012. We urge 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. While the obesity rates among children between the ages of 2-5 have significantly decreased over the past decade, more than one-third of adults are obese and 17 percent of children are obese. Obesity, diet and inactivity are cross-cutting risk factors that contribute significantly to heart disease, cancer, stroke and diabetes. CDC funds programs to encourage the consumption of fruits and vegetables, encourage sufficient exercise and develop other habits of healthy nutrition and physical activity.

Arthritis is the most common cause of disability in the U.S., striking more than 53 million Americans of all ages, races and ethnicities. CDC's Arthritis Program plays a critical role in addressing this growing public health crisis and working to improve the quality of life for individuals affected by arthritis and we urge you to support adequate funding for the program.

CDC provides national leadership in helping control the HIV epidemic by working with community, state, national, and international partners in surveillance, research, prevention and evaluation activities. CDC estimates that about 1.2 million Americans are living with HIV with 12.8 percent undiagnosed. The number of people living with HIV is increasing as new drug therapies are keeping HIV-infected persons healthy longer and dramatically reducing the death rate. 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. CDC estimates that 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 oversees immunization programs for children, adolescents and adults, and is a global partner in the ongoing effort to eradicate polio worldwide. Influenza vaccination levels remain low for adults. Levels are substantially lower for pneumococcal vaccination among adults as well, with significant racial and ethnic disparities in vaccination levels persisting among the elderly. Childhood immunizations provide one of the best returns on investment of any public health program. For every dollar spent on childhood vaccines to prevent thirteen diseases, more than $10 is saved in direct and indirect costs. Over the past 20 years, CDC estimates childhood immunizations have prevented 732,000 deaths and 322 million illnesses. We urge you to restore the president's proposed cuts to the Section 317 Immunization program.

Injuries are the leading causes of death for people ages 1-44. Unintentional and violence-related injuries, such as older adult falls, prescription drug overdose, child maltreatment and sexual violence, account for approximately 27 million emergency department visits each year. In 2013, injury and violence cost the U.S. approximately $671 billion in direct and indirect medical costs. The National Center for Injury Prevention and Control must be adequately funded to prevent injuries and minimize their consequences.

Birth defects affect one in 33 babies and are a leading cause of infant death in the U.S. Children with birth defects who survive often experience lifelong physical and mental disabilities. Over 500,000 children are diagnosed with a developmental disability and it is estimated that up to 57 million people in the U.S currently live with a disability. The National Center on Birth Defects and Developmental Disabilities conducts important programs to prevent birth defects and developmental disabilities and promote the health of people living with disabilities and blood disorders and must be adequately funded.

The National Center for Environmental Health works to protect public health by helping to control asthma, protect from threats associated with natural disasters and climate change, reduce, monitor and track exposure to lead and other hazards and ensure access to safe and clean water. We urge you to support the president's request for the Climate and Health and Safe Water programs, increase funding for the Childhood Lead Poisoning Prevention, Environmental Health Laboratory and Asthma programs, restore proposed cuts to the National Environmental and Public Health Tracking Network and restore funding for the Built Environment and Health program which was eliminated in 2016.

In order to meet the many ongoing public health challenges outlined above, we urge you to support our **FY 2017 request of $7.8 billion for CDC's programs.**

Jared Frost, Senior Associate, Legislative Affairs
American College of Physicians

Statement for the Record of the American College of Physicians to the

House Appropriations Subcommittee on Labor, Health and Human Services,

Education, and Related Agencies

Re: FY2017 Appropriations, Department of Health and Human Services

April 15, 2016

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 FY2017. ACP is the largest medical specialty organization and the second-largest physician group in the United States. ACP members include 143,000 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 FY2017, ACP is urging funding for the following proven programs to receive appropriations from the Subcommittee:

- Health Resources Services Administration (HRSA), $7.48 billion;
- Title VII, Section 747, Primary Care Training and Enhancement, HRSA, at no less than $71 million;
- National Health Service Corps (NHSC), HRSA, $380 million in total program funding, including at least $20 million through discretionary appropriations;
- Agency for Healthcare Research and Quality (AHRQ), $364 million.

The United States is facing a shortage of physicians in key specialties, notably in general internal medicine and family medicine—the specialties that provide primary care to most adult and adolescent patients. With enactment of the Affordable Care Act (ACA), the Congressional Budget Office has estimated, as of March 2016, the demand for primary care services will increase with the addition of 38 million Americans receiving access to health insurance, including an additional 19 million under Medicaid/CHIP, by 2026. With increased demand, current projections indicate there will be a shortage of 14,900 to 35,600 primary care physicians by 2025. (IHS Inc., prepared for the Association of American Medical Colleges. 2016 Update, The Complexities of Physician Supply and Demand: Projections from 2013 to 2025. April 5, 2016. Accessed at: https://www.aamc.org/download/458082/data/2016_complexities_of_supply_and_demand_projections.pdf). HRSA is responsible for improving access to health-care services for people who are uninsured, isolated or medically vulnerable. Without critical funding for vital workforce programs, this physician shortage will only grow worse. A strong primary care infrastructure is an essential part of any high-functioning healthcare system, with **over 100 studies showing primary care is associated with better outcomes and lower costs of care** (http://www.acponline.org/advocacy/where_we_stand/policy/primary_shortage.pdf). **Therefore we urge the Subcommittee to provide $7.48 billion for discretionary HRSA programs for FY2017 to improve the care of medically underserved Americans by strengthening the health workforce.**

The health professions' education programs, authorized under Title VII of the Public Health Service Act and administered through (HRSA), support the training and education of health care providers to enhance the supply, diversity, and distribution of the health care workforce, filling the gaps in the supply of health professionals not met by traditional market forces, and are critical in helping institutions and programs respond to the current and emerging challenges of ensuring that all Americans have access to appropriate and timely health services. Within the Title VII program, we urge the Subcommittee to fund the **Section 747, Primary Care Training and Enhancement** program at $71 million, in order to maintain and expand the pipeline for individuals training in primary care. The Section 747 program is the only source of federal training dollars available for general internal medicine, general pediatrics, and family medicine. For example, general internists, who have long been at the frontline of patient care, have benefitted from Title VII training models emphasizing interdisciplinary training that have helped prepare them to work with other health professionals, such as physician assistants, patient educators, and psychologists. Without a substantial increase in funding, for the sixth year in a row, HRSA will not be able to carry out a competitive grant cycle for physician training; the nation needs new initiatives supporting expanded training in multi-professional care, the patient-centered medical home, and other new competencies required in our developing health system.

The College urges $380 million in total program funding for the **National Health Service Corps** (NHSC), as requested in the President's FY2017 budget; this amount includes $310 million in existing mandatory funds under current law, $20 million in discretionary spending through new

budget authority, and $50 million in new mandatory funding. Since the enactment of the ACA, the NHSC has awarded over $1.5 billion in scholarships and loan repayment to health care professionals to help expand the country's primary care workforce and meet the health care needs of underserved communities across the country. With a field strength of 9,700 primary-care clinicians, NHSC members are providing culturally competent care to over 10 million patients at 16,000 NHSC-approved health care sites in urban, rural, and frontier areas. The increase in funds would expand NHSC field strength to over 10,150 and would serve the needs of more than 10.7 million patients, helping to address the health professionals' workforce shortage and growing maldistribution. The programs under NHSC have proven to make an impact in meeting the health care needs of the underserved, and with increased appropriations, they can do more. For FY2016, the NHSC's funding situation was particularly dire and faced a funding cliff because its mandatory funding was set to expire and was without any budget authority to at least temporarily continue operations with discretionary funding. The College was therefore pleased that the *Medicare Access and CHIP Reauthorization Act*, H.R. 2, continued the NHSC at its FY2015 funding level for FY2016 and FY2017 (through an extension of mandatory resources). However, with FY2017 being the last year of enacted dedicated mandatory funding, ACP believes that the Corps urgently needs discretionary funding to be able continue its operations should it face another mandatory funding cliff.

The **Agency for Healthcare Research and Quality** (AHRQ) is the leading public health service agency focused on health care quality. AHRQ's research provides the evidence-based information needed by consumers, clinicians, health plans, purchasers, and policymakers to

make informed health care decisions. The College is dedicated to ensuring AHRQ's vital role in improving the quality of our nation's health and recommends a budget of $364 million, restoring the agency to its FY2015 enacted level after a cut in FY2016. This amount will allow AHRQ to help providers help patients by making evidence-informed decisions, fund research that serves as the evidence engine for much of the private sector's work to keep patients safe, make the healthcare marketplace more efficient by providing quality measures to health professionals, and, ultimately, help transform health and health care.

In conclusion, the College is keenly aware of the fiscal pressures facing the Subcommittee today, but strongly believes the United States must invest in these programs in order to achieve a high performance health care system and build capacity in our primary care workforce and public health system. The College greatly appreciates the support of the Subcommittee on these issues and looks forward to working with Congress as you begin to work on the FY2017 appropriations process.

Eileen M. Healy

Executive Director

Independence Northwest, Inc.

1183 New Haven Road, Suite 200

Naugatuck, CT 06770

I am writing to support the National Council on Independent Living's request to Congress to reaffirm your commitment to the more than 57 million Americans disabilities by increasing funding in the HHS appropriations for Centers for Independent Living (CILs). I am asking that you increase funding by $200 million, for a total of $301 million for the Independent Living line item in FY 2017. While increasing federal funding for CILs is much needed and deserved, it is critically important for the CILs in Connecticut. Governor Malloy has zeroed out the state budget line for the CILs that would result in an annual $105K loss to each of CT's CILs. Connecticut CILs have been doing more for our citizens with disabilities despite annual budget reductions and rescissions over the last 5 years. And as other human services state budget lines are cut or severely reduced, the lack of these resources only creates greater demand on the CILs. CT CILS cannot meet our federal mandates without increased funding at the federal level.

CILs are cross-disability, non-residential, community-based, nonprofit organizations that are designed and operated by individuals with disabilities. CILs are unique in that they are directly governed and staffed by people with all types of disabilities and all ages, including people with mental, physical, sensory, cognitive, and developmental disabilities. Each of the 365 federally funded centers provides five core services: information and referral, individual and systems

advocacy, peer support, independent living skills training, and transition services, which was added with the passage of the Workforce Innovation and Opportunity Act (WIOA). From 2012-2014, nationally CILs provided the core services to nearly 5 million people with disabilities, and provided additional services such as housing assistance, transportation, personal care assistants, and employment services to hundreds of thousands of individuals. During this same period, prior to transition being added as a core service, CILs transitioned 13,030 people with disabilities from nursing homes and other institutions into the community, saving millions in institutional costs for states and the federal government.

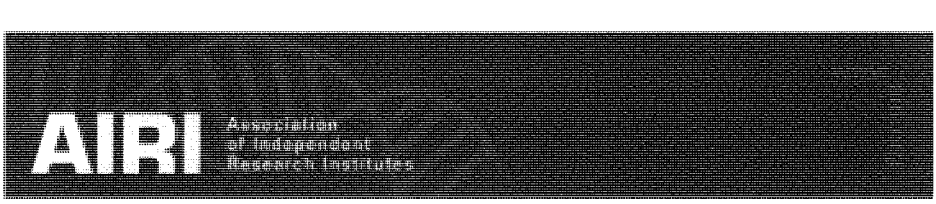
Transition services was added as a fifth core service with the 2014 reauthorization of the Rehabilitation Act within the Workforce Innovation and Opportunity Act. Transition services include the transition of individuals with significant disabilities from nursing homes and other institutions to home and community-based residences with appropriate supports and services, assistance to individuals with significant disabilities at risk of entering institutions to remain in the community, and the transition of youth with significant disabilities to postsecondary life. This core service is vital to achieving full community participation for people with disabilities.

Every day, CILs are fighting to ensure that people with disabilities gain and maintain control over our own lives, and achieve independent living in their communities. We know that this cannot occur when people reside in institutional settings. Opponents of deinstitutionalization say that allowing people with disabilities to live in the community will result in harm. We know that the 13,030 people with disabilities who CILs successfully transitioned out of nursing homes and institutions from 2012-2014 prove otherwise. Additionally, when services are delivered in an

individual's home, the result is a tremendous cost savings to Medicaid, Medicare, and states. Community-based services enable people with disabilities to become less reliant on long-term government supports, and they are significantly less expensive than nursing home placements. We are grateful that Congress demonstrated their understanding and support for community-based services when WIOA was passed and transition was added as a fifth core service.

Since transition services were added as a core service, the need for funding is critical. Moreover, CILs need additional funding to restore the devastating cuts to the Independent Living program, make up for inflation costs, and address the increased demand for independent living services. In 2016, the Independent Living Program is receiving $2.5 million less in funding than it was in 2010. It is simply not possible to meet the increasing demand for services and effectively provide transition services without additional funding. Increased funding should be reinvested from the billions currently spent to keep people with disabilities in costly Medicaid nursing homes and institutions and out of mainstream society.

Centers for Independent Living play a crucial role in the lives of people with disabilities, and work tirelessly to ensure that people with disabilities have a real choice in where and how they live, work, and participate in the community. Additionally, CILs are an excellent service and a bargain for America, keeping people engaged with their communities, saving taxpayer money, and assisting people in obtaining and maintain employment which creates new taxpayers. NCIL is dedicated to increasing the availability of the invaluable and extremely cost-effective services CILs provide, and they have submitted written testimony with a similar request. I strongly support NCIL's testimony.



Written Testimony for the Record Submitted by
Association of Independent Research Institutes
for the
Subcommittee on Labor, Health and Human Services, Education and Related Agencies
Committee on Appropriations, United States House of Representatives

Fiscal Year 2017 Funding for the
National Institutes of Health, Department of Health and Human Services

April 15, 2016

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 continue to improve our nation's health, sustain our leadership in medical research, and remain competitive in today's global information and innovation-based economy. **AIRI urges the Subcommittee to provide at least $34.5 billion for NIH in fiscal year (FY) 2017.** This testimony is submitted by Erica Froyd, AIRI Washington Office.

The $2 billion increase in the final FY 2016 omnibus appropriations bill was a much needed increase for NIH. This increase is essential to addressing current and emerging health challenges and building a healthier nation. However, this increase did not make up for funds cut by sequestration in FY 2013 nor did it restore the purchasing power NIH has lost over the past decade. In fact, despite budget increases in each of the past two fiscal years, the NIH budget

remains lower than it was in FY 2012 in actual dollars, and since 2003, NIH funding has declined by 22 percent after adjusting for biomedical inflation.

While the President's FY 2017 budget request for NIH would provide a much needed next step by increasing NIH funding above biomedical inflation, AIRI believes that the ongoing and emerging health challenges confronting the United States and the world, and the unparalleled scientific opportunities to address these burdens demand a funding level of at least $34.5 billion in FY 2017. AIRI also urges Congress and the Administration to work in a bipartisan manner to end sequestration and the continued cuts to medical research that squander invaluable scientific opportunities, discourage young scientists, threaten medical progress and continued improvements in our nation's health, and jeopardize our economic future.

AIRI is a national organization of more than 80 independent, non-profit research institutes that perform basic and clinical research in the biological and behavioral sciences. AIRI institutes vary in size, with budgets ranging from a few million to hundreds of millions of dollars. In addition, each AIRI member institution is governed by its own independent Board of Directors, which allows our members to focus on discovery-based research while remaining structurally nimble and capable of adjusting their research programs to emerging areas of inquiry. Researchers at independent research institutes consistently exceed the success rates of the overall NIH grantee pool, and they receive about ten percent of NIH's peer-reviewed, competitively-awarded extramural grants.

The partnership between NIH and America's scientists, research institutions, universities, and medical schools is a unique and highly-productive relationship, leveraging the full strength of our nation's research enterprise to foster discovery, improve our understanding of the underlying cause of disease, and develop the next generation of medical advancements that deliver more treatments and cures to patients. Not only is NIH research essential to advancing health, it also plays a key economic role in communities nationwide. Approximately 84 percent of the NIH's budget goes to more than 300,000 research positions at over 2,500 universities and research institutions located in every state.

The federal government has an irreplaceable role in supporting medical research. No other public, corporate, or charitable entity is willing or able to provide the broad and sustained funding for the cutting edge research necessary to yield new innovations and technologies of the future. NIH supports long-term competitiveness for American workers, forming one of the key foundations for U.S. industries like biotechnology, medical device and pharmaceutical development, and more. Unfortunately, continued erosion of the national commitment to medical research threatens our ability to support a medical research enterprise that is capable of taking full advantage of existing and emerging scientific opportunities.

The NIH model for conducting biomedical research, which involves supporting scientists at universities, medical centers, and independent research institutes, provides an effective approach to making fundamental discoveries in the laboratory that can be translated into medical advances that save lives. AIRI member institutions are private, stand-alone research

centers that set their sights on the vast frontiers of medical science. AIRI institutes are specifically focused on pursuing knowledge around the biology and behavior of living systems and applying that knowledge to improve human health and reduce the burdens of illness and disability.

AIRI member institutes are especially vulnerable to reductions in the NIH budget, as they do not have other reliable sources of revenue to make up the shortfall. In addition to concerns over funding, AIRI member institutes oppose legislative provisions – such as directives to reduce the salary limit for extramural researchers – which would harm the integrity of the research enterprise and disproportionately affect independent research institutes. Such policies hinder AIRI members' research missions and their ability to recruit and retain talented researchers. AIRI also does not support legislative language limiting the flexibility of NIH to determine how to most effectively manage its resources while funding the best scientific ideas.

AIRI member institutes' flexibility and research-only missions provide an environment particularly conducive to creativity and innovation. Independent research institutes possess a unique versatility and culture that encourages them to share expertise, information, and equipment across research institutions, as well as neighboring universities. These collaborative activities help minimize bureaucracy and increase efficiency, allowing for fruitful partnerships in a variety of disciplines and industries. Also, unlike institutes of higher education, AIRI member institutes focus primarily on scientific inquiry and discovery, allowing them to respond quickly to the research needs of the country.

AIRI members are located in 26 states, including many smaller or less-populated states that do not have major academic research institutions. In many of these regions, independent research institutes are major employers and local economic engines, and they exemplify the positive impact of investing in research and science.

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

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

AIRI thanks the Subcommittee for its important work dedicated to ensuring the health of the nation, and we appreciate this opportunity to urge the Subcommittee to **provide at least $34.5 billion for NIH in the FY 2017 appropriations bill**.

Outside Witness Testimony – Fiscal Year 2017 Appropriations

Submitted by:
WestCare Foundation

Prepared for:
The United States House Committee on Appropriations
Subcommittee on Labor, Health and Human Services, and Education, and Related Agencies

Agencies:
Centers for Disease Control, Substance Abuse and Mental Health Services Administration

April 15, 2016

WestCare Foundation respectfully submits this testimony to the U.S. House Appropriations Subcommittee on Labor, Health and Human Services, and Education, and Related Agencies (LHHS) regarding Fiscal Year (FY) 2017 appropriations for the Center for Disease Control (CDC) Prevention for States Program, a funding request of $80 million, and the Substance Abuse and Mental Health Services Administration (SAMHSA), requesting sufficient funding to address the opioid and prescription drug epidemic.

Each day, 46 people in the United States die from overdose of prescription painkillers[1]. According to the CDC, people in rural communities are nearly twice as likely to overdose on prescription pain medications as people in cities[2]. Prescription drug and opioid abuse is a public health crisis of significant proportion, in which underserved, rural areas are hit the hardest. Offering a full continuum of services to individuals with substance use disorders (SUD), including evidence-based prevention, early intervention and treatment efforts, is a necessary and comprehensive approach to combatting prescription drug overdose and sustaining recovery.

WestCare Foundation is a national non-profit organization that provides a wide array of health and human services in both outpatient and residential environments in nearly 20 States and the Pacific and Caribbean Islands. The Foundation provides comprehensive, wrap-around substance abuse and mental health services for children, adolescents, adults, and families, with an emphasis on serving underrepresented populations in rural areas. WestCare programs have shown significant outcomes in treating veteran and criminal justice populations returning to their communities through recovery supports such as housing, education, employment and other transitional services.

As a national substance use disorder provider, WestCare Foundation recognizes the magnitude of the prescription drug and opioid public health crisis our nation faces, and emphasizes the collaborative role of states, local communities, and service providers in preventing prescription

[1] Center for Disease Control (CDC): http://www.cdc.gov/vitalsigns/opioid-prescribing/ (2014)
[2] Center for Disease Control (CDC): http://www.cdc.gov/vitalsigns/painkilleroverdoses/ (2011)

drug overdoses, in addition to the importance of a continuum of care in effectively curbing substance use and mental health disorders through affordable and accessible care.

Center for Disease Control (CDC)

WestCare Foundation supports the Administration's FY 2017 request for $80 million for prescription drug overdose prevention programming at the Centers for Disease Control (CDC), $10 million above FY 2016 enacted levels.

The Center for Disease Control's (CDC) Prescription Drug Overdose Prevention for States Program (Prevention for States) is an initiative implemented in 2015 to provide state health departments with resources and support needed to advance interventions for preventing prescription drug overdoses within four key strategy areas: 1) Enhancing and maximizing state Prescription Drug Monitoring Programs (PDMPs) 2) Implementing community or insurer/health systems interventions 3) Conducting policy evaluations and 4) Developing and implementing rapid response projects. Due to the effectiveness of the program and the rising need, CDC received substantial increases in FY 2015 of $20 million, and in FY 2016, of $50 million dollars, to expand the state prevention activities to a national scale.

To ensure accountability, measurable outcomes and tracked progress, CDC is undergoing an evaluation of the program in order for measures to inform program improvements to achieve the highest public health impact possible as this program continues to grow and expand.

In FY 2017, the President's budget requests $80 million for prescription drug overdose prevention to promote opioid prescribing guideline dissemination and uptake. The Administration's budget proposal includes funding to continue and expand upon state support for Prescription Drug Overdose Prevention Programs in all 50 states and Washington, D.C., and continue to allow rigorous monitoring and evaluation and improvements in data quality.

In Fiscal Year 2017, WestCare Foundation supports the Administration's appropriations request for prescription drug overdose prevention of $80,000,000. This investment will increase accountability for States and allow States to advance and expand interventions for preventing prescription drug overdoses.

Given the prevalence of prescription drug and opioid abuse in rural areas throughout the nation, **WestCare recommends CDC outline a new strategic goal within the Prescription Drug Overdose Prevention for States Program dedicated to rural outreach,** engaging underserved communities through the existing U.S. Department of Agriculture (USDA) Cooperative Extension Service program (Extension Program).

By utilizing existing infrastructure such as Extension Programs, we can build on and connect services already underway such as SAMHSA Block Grants, SAMHSA Drug Free Communities, CDC Prevention for States, and HRSA grantees and streamline federal efforts to increase local and federal collaboration. Lack of local-federal and interagency coordination has impeded efficient, collaborative efforts among local stakeholders.

In February 2016, Secretary Tom Vilsack of USDA announced the "Rural America Opioid Initiative" to address the shortage in substance abuse services in rural areas. This interagency initiative has potential to serve as an effective vehicle in coordinating federal efforts to combat the opioid and heroin public health crisis in rural America. Through interagency coordination between the CDC and USDA, states and local communities can capitalize on existing programs like the USDA Extension Program and the CDC Prevention for States Program. Specifically, WestCare recommends that the CDC Prevention for States Program require grantees to provide Extension Offices with the resources, best practices, and technical expertise necessary to guide and assist local communities and rural SUD treatment providers in expanding treatment capacity and coordinating federal, state, and local opioid initiatives and funding streams at the local level.

WestCare respectfully recommends the following report language be inserted into the Fiscal Year 2017 Labor, Health and Human Services, Education, and Related Agencies Appropriations Bill: "the Committee directs the agency [CDC] to offer a new Prescription Drug Overdose Prevention for States Program competition [in Fiscal Year 2017] that incorporates a strategic goal to implement effective prescription drug overdose prevention in underserved rural areas, provided that up to 2% of funds under the program may be retained for an annual national summit on opioid treatment in rural communities."

Substance Abuse and Mental Health Services Administration (SAMHSA)

In FY 2017, WestCare Foundation supports increased investment to address prescription opioid abuse and heroin use, and is encouraged by the significant attention to substance use disorder treatment expansion, provided that medication-assisted-treatment is coupled with the full continuum of behavioral therapy and recovery support services. As physicians become gate keepers it is also imperative that they are highly qualified in diagnosing behavioral health disorders, treating addiction as a disease, proper pain prescribing, providing person-centered recovery plans, and making appropriate referrals to behavioral health specialists as they would for another health disorder.

WestCare Foundation applauds the Administration's and Congress' attention to the opioid and heroin epidemic, but recommends that any investment in medication-assisted treatment emphasize and provide flexibility for individualized, patient-centered behavioral and recovery support services. Substance addiction is a chronic, relapsing disease with prescribed care regimens that are often comparable to diabetes or heart disease, requiring patient education, treatment, rehabilitation, and consistent management of the disease upon recovery. Treatment modality, length of stay and service provision must be taken into consideration and will vary depending on the duration, dose and type of substance use, as well as the age of first initiation, trauma experienced, and other physical and mental health co-occurring disorders.

As with other chronic conditions treated with medication, medication-assisted treatment may facilitate stabilization and recovery for an opioid disorder. However, similar to a diabetic who receives insulin without changing their behavior and lifestyle through diet and exercise, an individual suffering from opioid addiction who receives medication-assisted treatment without complementary behavioral and recovery support services may not achieve sustained recovery.

Medication-assisted-treatment used in combination with necessary behavioral support services may help substance-addicted individuals to sustain their recovery.

SUDs are present on a wide spectrum of severity, often with co-occurring mental health and primary care health issues. To address the range of issues, WestCare provides differentiated programs across the continuum of care – services to accompany medication-assisted treatment. WestCare's wrap-around services include outpatient and residential treatment programs that include assessment, individual and group counseling, and case management; family and transitional education; vocational education; recreational therapy; health and mental health promotion; permanent and temporary supportive housing; and other community and peer supports.

One of the most pressing barriers to comprehensive services is workforce capacity and access to treatment. People seeking treatment are usually at their lowest point and impressionable. When forced to wait for treatment service, hopelessness can manifest and increase the likelihood for relapse. Unfortunately, the existing community-based system of care for heroin and opioid disorders is restricted by the Institute of Mental Disease (IMD) exclusion at a time when greater capacity is an essential respond to the crisis.

Medication-assisted treatment has been shown to improve patient survival, increase retention in treatment, decrease illicit opiate use and other criminal activity among people with substance use disorders, increase patients' ability to gain and maintain employment, improve birth outcomes among women who have substance use disorders and are pregnant[3].

Despite this evidence-based approach and proven effectiveness, medication-assisted-treatment is greatly underused. According to SAMHSA, the number of heroin admissions with treatment plans that included receiving medication-assisted opioid therapy fell from 35% in 2002 to 28% in 2010[3]. Slow adoption of these treatment options is partly due to misconceptions about substituting one drug for another and lack of training for physicians. Now, medication-assisted treatment is being looked to as a primary and sustainable method to provide comprehensive treatment.

The CDC Guideline for Prescribing Opioids for Chronic Pain released in March of 2016 recommends clinicians "offer or arrange evidence-based treatment (usually medication-assisted treatment with buprenorphine or methadone in combination with behavioral therapies) for patients with an opioid use disorder[4]." As an extension, the CDC points to studies that suggest using behavioral therapies, in combination with treatments like methadone maintenance therapy or buprenorphine, can reduce opioid misuse and increase retention during maintenance therapy and improve compliance after detoxification[5].

As both providers and policy-makers look to medication-assisted treatment models, the importance of behavioral therapy and full recovery support cannot be overstated. Therefore, **WestCare Foundation respectfully requests that any funding appropriated by Congress for medication-assisted treatment include report language explicitly stating "medication-assisted treatment**

---

[3] SAMHSA Treatment Episode Data Set (TEDS) 2002-2010: http://store.samhsa.gov/product/2000-2010-National-Admissions-to-Substance-Abuse-Treatment-Services/SMA12-4701

[4] CDC Guideline for Prescribing Opioids for Chronic Pain — United States, 2016: http://www.cdc.gov/mmwr/volumes/65/rr/rr6501e1.htm

in conjunction with behavioral and recovery support services" as an allowable use of medication-assisted treatment funds. The intention is to provide sufficient flexibility to allow substance use disorder treatment providers to meet local needs of their individual communities and target vulnerable populations such as pregnant women and veterans.

In closing, WestCare Foundation recognizes the fiscal realities of the federal budget but remains encouraged by Congress' strong commitment to addressing our nation's substance abuse public health crisis. We support the highest possible funding for mental health and substance use disorder treatment in FY 2017, and believe that through greater coordination of existing programs we can improve and better document treatment outcomes for people who suffer from addictions and or co-occurring disorders. We strongly encourage the Subcommittee not to overlook the need of coordination, capacity building, and the break-down of federal funding silos at the most local levels, particularly in rural communities. We further urge the Subcommittee not to view medication-assisted treatment as a "silver bullet," quick solution to our nation's opioid public health crisis – medication must be paired with complementary behavioral support services to achieve long-term, sustainable recovery. We look forward to collaborating on the FY 2017 appropriations process as Congress looks to invest and direct resources to this critical, national issue.

CONSORTIUM *of* SOCIAL SCIENCE ASSOCIATIONS

1701 K STREET NW, SUITE 1150 • WASHINGTON, DC 20006 • PHONE: (202) 842-3525 • EMAIL: ALSHARPE@COSSA.ORG • WWW.COSSA.ORG

Testimony in Support of Fiscal Year 2017 Funding for the National Institutes of Health (NIH), Centers for Disease Control and Prevention (CDC), National Center for Health Statistics (NCHS), Agency for Healthcare Research and Quality (AHRQ), the Institute of Education Sciences (IES), and International Education and Foreign Language Programs

Prepared for the Subcommittee on Labor, Health and Human Services, Education and Related Agencies, Committee on Appropriations, U.S. House of Representatives
Submitted by Angela L. Sharpe, MG, Deputy Director
Consortium of Social Science Associations

April 15, 2016

Mr. Chairman and Members of the Subcommittee, the Consortium of Social Science Associations (COSSA) appreciates and welcomes the opportunity to comment on the Fiscal Year (FY) 2017 appropriations of the agencies under the Subcommittee's jurisdiction. **COSSA recommends that the National Institutes of Health (NIH) receive at least $34.6 billion in FY 2017 and urges the Subcommittee to appropriate $7.8 billion for the Centers for Disease Control and Prevention (CDC), $170 million for the National Center for Health Statistics (NCHS), $364 million for the Agency for Healthcare Research and Quality (AHRQ), $728 million for the Institute of Education Sciences (IES), and $78.7 million for the Department of Education's International Education and Foreign Language programs.**

COSSA serves as a united voice for a broad, diverse network of organizations, institutions, communities, and stakeholders who care about a successful and vibrant social science research enterprise. It represents the collective interests of all fields of social and behavioral science research, including but not limited to sociology, anthropology, political science, psychology, economics, statistics, language and linguistics, population studies, law, communications, educational research, criminology and criminal justice research, geography, history, and child development. It is appreciative of the Subcommittee's and the Congress' continued support of NIH, CDC, NCHS, AHRQ, IES, and Title VI and Fulbright-Hays programs. Strong, sustained funding for these agencies is essential to our national priorities of better health and economic revitalization.

NIH (at least $34.6 billion), U.S. Department of Health and Human Services

Since 2003, NIH funding has declined by 23 percent after adjusting for biomedical inflation, despite recent budget increases provided by the Congress the past two fiscal years. The agency's

budget remains lower than it was in FY 2012 in actual dollars. COSSA appreciates the Subcommittee's leadership and its long-standing bipartisan support of NIH, as demonstrated by the $2 billion increase provided in the FY 2016 omnibus spending bill. There are, however, ongoing and emerging health challenges confronting the United States and the world. To that end, **COSSA believes that to address these challenges the NIH requires a funding level of at least $34.6 billion in FY 2017, representing 5 percent real growth above the projected rate of biomedical inflation.**

As this Committee knows, the NIH mission is to support scientifically rigorous, peer/merit-reviewed, investigator-initiated research, including basic and applied behavioral and social science research, in fulfilling its mission: "Science in pursuit of fundamental knowledge about the nature and behavior of living systems and the application of that knowledge to enhance health, lengthen life and reduce illness and disability." **COSSA, however, remains extremely concerned about continued criticism of the NIH's funding decisions and the accompanying mischaracterization of NIH-supported research. The ongoing targeting of specific grants produces a chilling effect across the scientific community.**

The behavioral and social sciences regularly make important contributions to the well-being of this nation. Due in large part to the behavioral and social science research sponsored by the NIH, we are now aware of the enormous role behavior plays in our health. At a time when genetic control over disease is tantalizingly close but not yet possible, knowledge of the behavioral influences on health is a crucial component in the nation's battles against the leading causes of morbidity and mortality: 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. Perhaps the grandest challenge we face is to understand the brain, behavior, and society— from responding to short-term pleasures to self-destructive behavior, such as addiction, to lifestyle factors that determine the quality of life, infant mortality rate and longevity. Congress' continued support of the BRAIN (Brain Research through Advancing Innovative Neurotechnologies) initiative is an important first step to begin to address these challenges.

As a result of strong Congressional commitment to the NIH in years past, our knowledge of the social and behavioral factors surrounding chronic disease health outcomes is steadily increasing. The NIH's behavioral and social science portfolio has emphasized the development of effective and sustainable interventions and prevention programs targeting those very illnesses that are the greatest threats to our health, but the work is just beginning.

Thanks to Congress, NIH has been given the resources support:

- Economic research, specifically, research on the linkages between socioeconomic status and health outcomes in the elderly and achievement and health outcomes in children;
- The translation of basic research to lifesaving interventions such infant massage, that enhance premature infants' weight gain and save lives;

- The Resources for Enhancing Alzheimer's Caregiver Health (REACH) program, which aims to help maintain the health of informal caregivers for the millions of American Alzheimer's patients who live at home;
- Research that led to understanding and improving ways that people communicate about health-related issues; and
- Research that increased our understanding adolescence peer pressure and smoking.

COSSA continues to applaud the Administration's *Precision Medicine Initiative* (PMI) and the NIH's involvement of its Office of Behavioral and Social Sciences Research (OBSSR) in the planning phase of this million-person cohort, including its commitment to including behavioral, physiological, and environmental measures. To this end, recent advances in mobile and wireless sensor technologies, also known as mHealth, to assess these behavioral, physiological, and environmental parameters are an integral aspect of this initiative. This technology has great potential to transform medical research. OBSSR has led the NIH's efforts in using, understanding, and training scientists in the use of mHealth which allows for more rapid and accurate assessment in modifying behavior, biological states, and contextual variables. Its support of the NIH mHealth Training Institutes is designed to break down to scientific silos by bringing together scientists from diverse fields to enhance the quality of mHealth research.

CDC ($7.8 billion) and NCHS ($170 million), U.S. Department of Health and Human Services

COSSA urges the Subcommittee to appropriate $7.8 billion for the Centers for Disease Control and Prevention (CDC), including $170 million for the CDC's National Center for Health Statistics. As the country's leading health protection and surveillance agency, the CDC works with state, local, and international partners to keep Americans safe and healthy. CDC relies on insights from the social and behavioral sciences to "explore the effects of behavioral, social, and cultural factors on public health problems" and to rigorously evaluate public health interventions, policies, and programs.[1]

Scientists from fields ranging from psychology, sociology, anthropology, and geography to health communications, social work, and demography work in every CDC Center to design, analyze, and evaluate behavioral surveillance systems, public health interventions, and health promotion and communication programs using a variety of both quantitative and qualitative methods. These scientists play a key role in the CDC's surveillance and monitoring efforts, which collect and analyze data to better target public health prevention efforts, and in identifying and understanding health disparities. The social and behavioral sciences also play an important role in the evaluation of CDC programs, helping policymakers make informed, evidence-based decisions on how to prioritize in a resource-scarce environment.

COSSA requests $170 million in budget authority for the National Center for Health Statistics (NCHS), the nation's principal health statistics agency. NCHS collects data on chronic disease

[1] Deborah Holtzman, M. Neumann, E. Sumartojo, and A. Lansky, "Behavioral and Social Sciences and Public Health at CDC," Morbidity and Mortality Weekly Report, December 22, 2006, http://www.cdc.gov/mmwr/preview/mmwrhtml/su5502a6.htm.

prevalence, health care disparities, emergency room use, teen pregnancy, infant mortality, causes of death, and rates of insurance, to name a few. It provides critical data on all aspects of our health care system through data cooperatives and surveys that serve as the gold standard for data collection around the world. Data from NCHS surveys like the National Health Interview Survey (NHIS), the National Health and Nutrition Examination Survey (NHANES), and the National Vital Statistics System (NVSS) are used by agencies across the federal government, state and local governments, public health officials, federal policymakers, and demographers, epidemiologists, health services researchers, and other scientists.

The requested increase for NCHS' budget would be used to support NCHS's major data collection systems—the National Vital Statistics System, the National Health Interview Survey, the National Health and Nutrition Examination Survey, and the National Health Care Surveys. The increase would also allow NCHS to continue its expansion of electronic death reporting, which improves the availability and specificity of data on deaths of public health importance, such as from prescription drug overdoses.

AHRQ ($364 million), U.S. Department of Health and Human Services

COSSA urges the Subcommittee to appropriate $364 million for the Agency for Healthcare Research and Quality (AHRQ). AHRQ funds research on improving the quality, safety, efficiency, and effectiveness of America's health care system. It is the only agency in the federal government with the expertise and explicit mission to fund research on improving health care at the provider level (i.e., in hospitals, medical practices, nursing homes, and other medical facilities). Its work complements—not duplicates—research supported by other HHS agencies.

AHRQ-funded research provides us with the evidence and tools we need to tackle some of the health care system's greatest challenges. For example, AHRQ-funded research:

- Has been instrumental in reducing healthcare-associated infections (HAIs) by 17 percent in five years, translating to 87,000 lives and nearly $20 billion in health care costs saved.
- Improves care for people suffering from multiple chronic conditions, a group that accounts for two-thirds of U.S. health care spending.
- Helps doctors make better decisions and improve patients' health by taking advantage of electronic health records and other IT advances.

AHRQ reports and data give us vital information about the state of the U.S. health care system and identify areas we can improve. The congressionally-mandated *National Healthcare Quality & Disparities Report* is the only comprehensive sources of information on health care quality and health care disparities among racial and ethnic minorities, women, children, and low-income populations. AHRQ's Medical Expenditure Panel Survey (MEPS) collects data on the how Americans use and pay for medical care, providing vital information on the impact of health care on the U.S. economy.

COSSA urges the Committee to ensure robust support for AHRQ's critical health services research.

IES ($728 million), U.S. Department of Education

The Institute of Education Sciences is the research arm of the Department of Education. COSSA recommends a funding level of $728 million for IES, which would restore funding for the Regional Educational Laboratories and the National Center for Special Education Research to the FY 2010 funding level. As this Committee knows, IES supports research and produces statistics and data to improve our understanding of education at many levels — early childhood, elementary and secondary education, and higher education. Research examining special education, rural education, teacher effectiveness, education technology, student achievement, reading and math interventions, and many other areas is also supported by IES.

More important, IES-supported research has substantially 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). There is an increasing demand for evidence-based practices in education. Adequate funding for IES would support studies that not only increase knowledge of the factors that influence teaching and learning, but also apply those findings to improve educational outcomes. Further, adequate funding will allow IES to continue to support this important research, data collection and statistical analysis, and dissemination. The COSSA-recommended funding level will also allow IES to build upon existing findings and to conduct much-needed new research.

International Education and Foreign Language Programs ($78.7 million), U.S. Department of Education

The Department of Education's International Education and Foreign Language programs play a significant role in developing a steady supply of graduates with deep expertise and high quality research on foreign languages and cultures, international markets, world regions, and global issues. COSSA urges a total appropriation of $78.7 million ($70.15 million for Title VI and $8.56 million for Fulbright-Hays) for these programs. This sum represents a modest increase in funding, which would broaden opportunities for students in international and foreign language studies. It would also allow for the strengthening of the U.S.' human resource capabilities on 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. Please do not hesitate to contact me should you require additional information.

Angela L. Sharpe, MG

Community Resources for Independent Living
439 'A' Street, Hayward, California 94541
(510) 881-5743
Fax (510) 881-1593
TDD (510) 881-0218
Tri-Valley (925) 484-1481
Tri-Cities (510) 794-5735

Ron Halog
Executive Director
Community Resources for Independent Living

I am writing to support the National Council on Independent Living's request for Congress to reaffirm your commitment to the more than 57 million Americans disabilities by increasing funding in the HHS appropriations for Centers for Independent Living (CILs). I am asking that you increase funding by $200 million, for a total of $301 million for the Independent Living line item in FY 2017.

CILs are cross-disability, non-residential, community-based, nonprofit organizations that are designed and operated by individuals with disabilities. CILs are unique in that they are directly governed and staffed by people with all types of disabilities, including people with mental, physical, sensory, cognitive, and developmental disabilities. Each of the 365 federally funded centers provides five core services: information and referral, individual and systems advocacy, peer support, independent living skills training, and transition services, which were added with the passage of the Workforce Innovation and Opportunity Act (WIOA). From 2012-2014, CILs provided the core services to nearly 5 million people with disabilities, and provided additional services such as housing assistance, transportation, personal care attendants, and employment services to hundreds of thousands of individuals. During this same period, prior to transition being added as a core service, CILs transitioned 13,030 people with disabilities from nursing homes and other institutions into the community.

Transition services were added as a fifth core service with the 2014 reauthorization of the Rehabilitation Act within the Workforce Innovation and Opportunity Act. Transition services include the transition of individuals with significant disabilities from nursing homes and other institutions to home and community-based residences with appropriate supports and services,

assistance to individuals with significant disabilities at risk of entering institutions to remain in the community, and the transition of youth with significant disabilities to postsecondary life. This core service is vital to achieving full participation for people with disabilities.

Every day, CILs are fighting to ensure that people with disabilities gain and maintain control over our own lives. We know that this cannot occur when people reside in institutional settings. Opponents of deinstitutionalization say that allowing people with disabilities to live in the community will result in harm. We know that the 13,030 people with disabilities who CILs successfully transitioned out of nursing homes and institutions from 2012-2014 prove otherwise. Additionally, when services are delivered in an individual's home, the result is a tremendous cost savings to Medicaid, Medicare, and states. Community-based services enable people with disabilities to become less reliant on long-term government supports, and they are significantly less expensive than nursing home placements. We are grateful that Congress demonstrated their understanding and support for community-based services when WIOA was passed and transition was added as a fifth core service.

Since transition services were added as a core service, the need for funding is critical. Moreover, CILs need additional funding to restore the devastating cuts to the Independent Living program, make up for inflation costs, and address the increased demand for independent living services. In 2016, the Independent Living Program is receiving $2.5 million less in funding than it was in 2010. It is simply not possible to meet the increasing demand for services and effectively provide transition services without additional funding. Increased funding should be reinvested from the billions currently spent to keep people with disabilities in costly Medicaid nursing homes and institutions and out of mainstream society.

Centers for Independent Living play a crucial role in the lives of people with disabilities, and work tirelessly to ensure that people with disabilities have a real choice in where and how they live, work, and participate in the community. Additionally, CILs are an excellent service and a bargain for America, keeping people engaged with their communities and saving taxpayer money. NCIL is dedicated to increasing the availability of the invaluable and extremely cost-effective services CILs provide, and they have submitted written testimony with a similar request. I strongly support NCIL's testimony.

PATH

Outside Witness Testimony for the Subcommittee on Labor, Health and Human Services, and Education, and Related Agencies

Prepared by: Brandon Ball, Policy & Advocacy Officer, PATH
Contact information: bball@path.org, 202.822.0033
Testimony is addressing HHS Global Health [CDC, NIH]

This testimony is submitted by Brandon Ball, Policy & Advocacy Officer, on behalf of PATH. PATH is appreciative of the opportunity afforded by Chairman Cole, Ranking Member DeLauro, and members of the Subcommittee on Labor, Health and Human Services, Education and Related Agencies to submit written testimony regarding fiscal year (FY) 2017 funding for global health programs within the US Department of Health and Human Services (HHS). PATH acknowledges the strong leadership the Committee has shown in supporting HHS' work in this area, and recommends that this support continue. This testimony is submitted on behalf of PATH, a leader in global health innovation. As an international nonprofit organization, PATH saves lives and improves health, especially among women and children. Accelerating innovation across five platforms—vaccines, drugs, diagnostics, devices, and system and service innovations—PATH harnesses its entrepreneurial insight, scientific and public health expertise, and passion for health equity. By mobilizing partners around the world, PATH takes innovation to scale, working alongside countries primarily in Africa and Asia to tackle their greatest health needs. With these key partners, PATH delivers measurable results that disrupt the cycle of poor health. **Therefore, we respectfully request that this Subcommittee ensure robust funding for global health programs within HHS in FY 2017—including $224 million for the Center for Disease Control and Prevention's (CDC's) global immunization programs, $25.5 million for CDC's malaria programs, $65.2 million for CDC's Division of Global Public Health Protection and Security, and $33.1 billion for the National Institutes of Health (NIH)—which capitalize on the agency's technical expertise to improve health and increase security, while bolstering the ability of partner countries to lead in the future.**

The vital role of HHS in global health and security

Recent outbreaks of Zika, Ebola, and measles have demonstrated that the health of US citizens is inherently connected to the health of people living around the globe. Global pandemics and increasing international travel only intensify Americans' vulnerability to diseases that have historically impacted communities outside our borders. For these and other reasons, HHS has been active in global health programs for decades. For example, within HHS, agencies such as CDC collaborate with partner governments to build public health infrastructure and expertise to track and combat diseases worldwide, while conducting research to support the development of new and improved technologies to better help us fight disease threats in the future.

HHS's Global Health Strategy (2011), currently being revised for 2016 and beyond, articulates the department's international role in guiding efforts to safeguard health globally. This role was further strengthened in HHS' central role in the Global Health Security Agenda, launched in 2014. These efforts—such as addressing antimicrobial resistance, and improving laboratory

safety and workforce development in more than 34 countries—help to better protect Americans' health and security, while increasing partner countries' ability to contain outbreaks and provide for the health of their citizens.

With continued funding for these activities, the department will be able to continue to strengthen health systems around the world, improve access to proven health interventions in communities where they are needed most, and invest in solutions to tomorrow's health and security challenges.

Using cost-effective strategies to save lives

One key strategy for achieving HHS' global health and security goals is immunization, with the majority of activities to ensure vaccine delivery overseen by CDC's Global Immunization Division, NIH and BARDA. Vaccines are one of the most impactful and cost-effective public health interventions available today. They have played an outsized role in the reduction—by half—of the number of child deaths since 1990. Worldwide, polio cases have dropped by more than 99 percent since 1988; measles deaths declined by 79 percent from 2000 through 2014; and 2 to 3 million deaths are averted each year through immunization. HHS has contributed significantly to this achievement. For example, thanks in part to HHS' role in global polio immunization efforts, including as a leading partner in the Global Polio Eradication Initiative, Southeast Asia, including India, was certified polio-free in March 2014. Nigeria has not had a case of polio in a year and half, and is expected to be certified polio-free next year if no further cases are reported. Only two countries (Afghanistan and Pakistan) remain endemic, down from more than 125 in 1988.

Globally, programs to immunize populations against a range of vaccine preventable diseases have been built on the foundation of polio vaccination efforts. In fact, polio and routine immunization programs have been a driving force behind strengthening public health systems in many of the world's least developed countries. As polio nears eradication, it is critical to maintain investment—in some cases transitioning funds that have previously been allocated under the heading of polio—to support activities that maintain and expand routine immunization and strengthen public health infrastructure.

Infrastructure and expertise created to address polio have not only reduced cases of that disease and expanded immunization to prevent other diseases, but have also been leveraged to address epidemics. For example, Nigeria was able to rapidly adapt its polio infrastructure and emergency operating center, built with CDC input and support, to respond to and contain an importation of Ebola in October 2014 in Lagos. Continued funding will enable HHS to further extend the delivery of lifesaving vaccines to where they are needed most, which will save lives and reduce the burden of disease globally.

Additionally, 2015 marks the halfway point of the Decade of Vaccines, an initiative which established a global framework (2010-2020) endorsed by the United States and 192 other nations with the aim of expanding access to immunization. While some progress has been made toward the goals outlined in the framework, and individual achievements in countries

have demonstrated what is possible with focused efforts, we are off track to meet many of the milestones outlined in the plan, and the delay means more lives lost. The US government is positioned to lead the way in accelerating progress toward the framework's goals, if coordination of efforts continues across various agencies. We are pleased to see HHS making strides toward strengthening the collective impact of its agencies engaged on global immunization, including the CDC and the NIH, among others, as well as across other departments of the US government. We urge the committee to continue to fully fund these efforts and encourage stronger coordination.

Fighting to eliminate malaria

In addition to its critical work in immunization, HHS has a long history in controlling and eliminating malaria. CDC, in particular, played a critical role in eliminating malaria from the United States. As a joint implementer of the President's Malaria Initiative (PMI), CDC continues to play a leading role in global control and elimination efforts alongside the US Agency for International Development. These efforts have made a significant impact. Between 2001 and 2015, an estimated 6.2 million lives were saved as a result of scaled-up malaria interventions. While incredible progress has been made, progress is fragile, and investments must be sustained to prevent reemergence of malaria in communities that have succeeded in controlling it. Last year, PMI set forth a five-year strategy, which includes an ambitious agenda to reduce malaria mortality by one-third from 2015 levels in PMI-supported countries, thereby achieving a greater than 80 percent reduction from PMI's 2000 baseline. The strategy also looks toward elimination of the disease regionally, in order to shrink malaria's footprint across the globe. Robust funding is required to execute on this goal.

With evidence of growing insecticide and drug resistance, CDC's Parasitic Diseases and Malaria program also plays a key role in malaria monitoring and surveillance, evaluation, and its work to ensure we have the new tools necessary to fight this ever-changing disease. Examples of CDC's contributions include evaluations of the impact of improved nets, insecticides, and strategic use of antimalarial drugs, as well as field trials of promising malaria vaccines, such as RTS,S, the malaria vaccine candidate furthest along in development globally, and recently recommended by the World Health Organization for pilot implementations in Africa.

While CDC's mandate has grown, their budget for malaria has been flat. Increased funding would better equip the agency to track the spread of drug and insecticide resistance, develop and deploy new tools, and ensure the more timely surveillance that is necessary for ultimate malaria elimination.

Protecting US leadership in global health R&D

While access to existing, proven health interventions—whether vaccines, bed nets, or drugs—must be extended, it is also critical to support research and development (R&D) into future technologies that can prevent existing and emerging global health threats. Investments made by the US government, including through the NIH, FDA, and CDC over the past three decades, have enabled many partners, including PATH, to advance innovations that have improved health and saved lives around the world. These innovations include new and improved

vaccines, such as an effective, low-cost vaccine against meningitis A, which historically caused devastating outbreaks each year in Africa's Meningitis Belt. Zero cases of meningitis A have occurred among the more than 235 million Africans vaccinated since 2010. We also leveraged US support to pioneer safe injection technologies that have helped to prevent millions of blood-borne infections. Thanks to a discovery made by scientists at NIH, PATH was able to develop a simple, rapid test for exposure to river blindness, a disease that affects 25 million people. This test was launched commercially last year and is an important tool in the fight to eliminate river blindness in Africa.

The promise of new global health technologies can only be realized when products are developed, tested, licensed, and scaled up for use globally. Investment in these activities at NIH, CDC, and FDA should continue. Furthermore, strengthened collaboration and coordination between HHS operating divisions and other US agencies funding new and improved drugs, diagnostics, vaccines, and devices will be critically important to better align R&D investments and global health program priorities across the US government to maximize the impact of US taxpayer dollars.

An investment in health, at home and around the world

With strong funding for global health programs within HHS, the department will be able to improve access to proven health interventions in the communities where they are needed most, while at the same time investing in solutions to tomorrow's challenges. By fully funding the global health and immunization-related accounts, the US can protect the health of Americans while ensuring that people everywhere have the opportunity to lead healthy lives and reach their full potential.

The CorpsNetwork
Strengthening America through service and conservation

www.corpsnetwork.org

Written Testimony for the Record for the House Appropriations Subcommittee on Labor, Health and Human Services, Education, and Related Agencies from: Mary Ellen Sprenkel, President & CEO

April 15, 2016

The Honorable Tom Cole
Chairman
Subcommittee on Labor, Health and Human Services, and Education
2358-B Rayburn House Office Building
Washington, DC 20515

The Honorable Rosa DeLauro
Ranking Member
Subcommittee on Labor, Health and Human Services, and Education
2358-B Rayburn House Office Building
Washington, DC 20515

Dear Chairman Cole and Ranking Member DeLauro,

We write to respectfully urge your support for the Corporation for National and Community Service (CNCS) in Fiscal Year 2017 Appropriations and for an increased funding level for CNCS to $1.47 billion which includes $720.1 million for AmeriCorps State and National; $35 million for the NCCC; $142.1 million for VISTA; $444.3 million for the National Service Trust (Education Awards); and $24.6 million for State Commissions.

Thank you for the opportunity to provide written testimony for the record, and for your work in holding the first hearing with the CEO of CNCS in many years. We appreciate your support for CNCS, and your thoughtful comments on the impact of AmeriCorps service whether through veteran's engagement, disaster recovery, or educational services. We also greatly appreciate your efforts in the FY16 Omnibus to ensure AmeriCorps received additional funding. While there are many critical priorities under your jurisdiction, we know programs like CNCS' AmeriCorps meet some of the most vital public needs in communities around the country, leverage significant additional private funding and resources, and save the government money in the long run. A recent study put the return on investment in AmeriCorps at 4:1.

The Corps Network (TCN) represents the nation's 130+ Service and Conservation Corps (Corps) as they harness the power of youth and veterans to tackle some of America's greatest challenges and transform their own lives. Corps are comprehensive youth development service programs that work in all states and the District of Columbia and enroll around 24,000 youth each year. Corps follow a model of adult mentors (Crewleaders) guiding crews of youth (Corpsmembers, ages 16-25 and veterans up to 35) which perform community and conservation service projects in urban areas or on public lands. Tied to those projects, Corpsmembers receive educational, workforce development, and supportive services. Corps enroll diverse Corpsmembers, and prioritize providing opportunity for disconnected youth to have opportunities to serve in AmeriCorps. Over 60% of Corpsmembers were below the poverty line, unemployed, not in school and had no High School Diploma/GED, or were formerly incarcerated or court-involved.

The CorpsNetwork
Strengthening America through service and conservation

www.corpsnetwork.org

As a result of CNCS' AmeriCorps State and National, AmeriCorps VISTA, and AmeriCorps NCCC, Corps are able to leverage additional match funds to accomplish a wealth of conservation, infrastructure improvement, and human service projects identified as critical by local communities and partners. Recently, 45 AmeriCorps members with Washington Conservation Corps were deployed in response to flooding in Grays Harbour County, WA and conducted damage assessments, debris removal, and volunteer support. Another instance of severe weather in Van, Texas led to the engagement of nine AmeriCorps members from American Youth Works Texas Conservation Corps in the set up and management of a volunteer reception center that saw more than 1,000 volunteers. Corps also work on other infrastructure projects like transportation and water infrastructure and specifically engage veterans in Conservation and Fire Corps and Native Americans through conservation and restoration projects on tribal land like in Acoma Pueblo and the Navajo Nation. Many Corps improve and preserve our public lands and national parks while others provide energy conservation services, including weatherization and alternative energy installation. Corps also restore natural habitats and create urban parks and gardens.

In particular, The Corps Network urges your support for the Summer Opportunity Youth Initiative. According to CNCS' budget justification, "The request includes an Opportunity Youth initiative that would enable up to 8,000 disconnected youth to serve as AmeriCorps members during the summer, giving them a chance to help their communities while exploring potential career paths, developing skills, and earning an education award they can use for college. CNCS is interested in expanding funding for summer service programs that expand opportunity for youth." There is a significant need to reengage disconnected youth, and help them get on a path to furthering their education and into the workforce.

The Corps Network is presently operating a full-time Opportunity Youth Service Initiative with support from CNCS to enroll thousands of out of school and out of work youth in national service environmental stewardship initiatives at Corps around the country. While serving, they gain career skills, hands on work experience, and advance their education. They also earn AmeriCorps education awards that help encourage them to enroll in postsecondary education/training. As of 2015, there are approximately 5.8 million young Americans who meet the definition of Opportunity Youth. These young men and women represent a social and economic opportunity: many of them are eager to further their education, gain work experience and help their communities, but need meaningful ways to do so. Not investing in these young people, and those that might be at-risk of fully disconnecting at 14 or 15, means greater cost to taxpayers and society in the hundreds of thousands of dollars later on as they remain disconnected.

CNCS has worked for many years in communities around the country and with non-profit organizations like ours to address the most pressing social challenges with significant buy-in from local public and private entities. We are pleased to be able to participate in new partnerships that CNCS has established through the President's National Service Task Force and urge your support for encouraging more of such partnerships. For example, The Corps Network

The CorpsNetwork
Strengthening America through service and conservation

www.corpsnetwork.org

has been able to enroll court-involved youth in AmeriCorps and partner them with mentors while helping them be seen as an asset to their community, not a liability. Additionally, we've worked with CNCS and the US Department of Agriculture to enroll AmeriCorps members in a 21st Century Conservation Service Corps to accomplish important work on public lands and help address the millions of dollars in backlogged maintenance and meet wildfire suppression and fighting needs.

As you can see, CNCS supports many important initiatives that engage a diverse population of youth serving in Corps including veterans, Native Americans and individuals with disabilities. With increasing strains on public support systems, it is more important than ever to support this type of community-needs-based service to fill-in the gaps of need. There is also significant demand for these positions, with all of our Corps being oversubscribed and CNCS reporting in 2011, 582,000 AmeriCorps applications were received with only 82,000 slots available. Through your support, we can provide more service opportunities for our youth to reengage in education, work, and their communities and get on a productive path for the United States' continued growth and prosperity.

Thank you for the opportunity to provide written testimony for the record. We again respectfully urge your support for CNCS and for increased funding of $1.47 billion for the Corporation for National and Community Service in Fiscal Year 2017. Thank you for your time and consideration of this testimony.
Sincerely,

Mary Ellen Sprenkel

Mary Ellen Sprenkel

President & CEO

1275 K Street, NW, Suite 1050, Washington, DC 20005 p: 202.737.6272 f: 202.737.6277

Testimony to the House Appropriations Subcommittee on Labor, Health and Human Services, Education and Related Agencies Concerning Programs in the Substance Abuse and Mental Health Services Administration, Health Resources and Services Administration, and Administration for Children and Families
By
American Psychiatric Association, Corporation for Supportive Housing, National Alliance to End Homelessness, National Alliance on Mental Illness, National Health Care for the Homeless Council, and Technical Assistance Collaborative

Contact: Eva Wingren
Phone: 202-715-3985 ext. 70
Email: eva.wingren@csh.org

April 15, 2016

The American Psychiatric Association, Corporation for Supportive Housing, National Alliance to End Homelessness, National Alliance on Mental Illness, National Health Care for the Homeless Council, and Technical Assistance Collaborative are national organizations who work at the intersection of mental health and substance abuse disorders, and homelessness. We work at the local, state, and federal levels to reorient systems and leverage resources to create permanent solutions to homelessness for the most vulnerable Americans, usually involving a combination of affordable housing and supportive services. As we enter the home stretch of ending homelessness among veterans and turn our attention to ending homelessness for other populations, it is essential that homeless services funded through the Substance Abuse and Mental Health Services Administration (SAMHSA), Health Resources and Services Administration (HRSA), and Administration for Children and Families (ACF) grow to keep pace with momentum from the housing sector. To this end, our organizations recommend the following:

- Allocate **$100 million,** the fully authorized level, for services for people experiencing homelessness within the Programs of Regional and National Significance (PRNS) accounts of both SAMHSA's Center for Mental Health Services and Center for Substance Abuse Treatment.
- Increase funding for the Projects for Assistance in Transition from Homelessness (PATH) program to **$75 million,** the fully authorized level.
- Allocate **$10 million** from PATH to a demonstration program to create permanent statewide coordination capacity for the SSI/SSDI Outreach, Access and Recovery (SOAR) program.
- Provide **$7.48 billion** for HRSA, including $5.1 billion in funding for health centers, and the extension of current mandatory funding of $3.6 billion for FY 2018 and FY 2019, as requested by the Administration. This would result in **$650.76 million** for the Health Care for the Homeless (HCH) program.
- Increase funding for the Runaway and Homeless Youth Act Programs to **$165 million**.

Background

In addition to housing resources through the Department of Housing and Urban Development, there is also a need for the Department of Health and Human Services to ensure that resources are available for services such as case management, landlord negotiation, connection to health services, counseling and medication management. Providers often use a combination of federal, state, local, foundation and privately raised funds to pay for the vital social services chronically homeless populations must have to stay housed.

While HUD has made significant housing investments, there is a need for HHS to increase its role in providing services resources for organizations to create supportive housing. Supportive housing residents frequently live with serious mental illness, substance use disorders or chronic health conditions, and to retain housing must have access to HHS funded services.

We know supportive housing works. In these tough budget times, it is important to use every public dollar as effectively as possible. We are proposing an increase to HHS Homeless Services Programs because these programs ultimately save tax payer dollars. Supportive housing ends the cycle of frequently and inappropriately using expensive social supports and institutional care that people with complex needs cannot break while homeless:

- **Reduced Health Care Costs**. In New York, reduced psychiatric hospitalizations resulted in an annual savings of $18,688 per person. In Denver and Los Angeles, annual reductions in physical health hospitalizations saved of $3,423 and $37,617 per person, respectively.
- **Lower Shelter Costs**. Large annual savings were also generated as a result of reductions in shelter use - $6,9191 and $6,8442 per person in New York and Denver, respectively.
- **Reduced Incarceration**. Savings from reductions in jail and prison use were smaller, but still significant. In New York, combined annual savings from jail and prison was $1,2981 per person, $6862 in Denver, and $2,1813 in Los Angeles.

Increasingly, organizations are able to access Medicaid reimbursement when the population is enrolled in Medicaid, the service is part of the benefit package and the provider is licensed to bill Medicaid. However, SAMHSA, HRSA, and ACF homeless programs are a vital flexible resource to cover services that Medicaid won't cover, and build provider capacity. In order to capitalize on this new resource, the Department of Health and Human Services must increase its investment in supportive housing services.

In addition, there are several other subpopulations experiencing either homelessness or housing instability that would benefit from increased social services oriented funding. On a small scale, HHS programs have targeted youth, veterans and families to ensure that all people who could benefit from mental health and substance use treatment can receive specialized support. However, without increased funding, communities will not be able to fully implement the supportive housing model for the hundreds of thousands of people who can benefit from it.

Detailed Program Descriptions

SAMHSA Support Services for Supportive Housing Projects

We recommend allocating $100 million for services in permanent supportive housing within SAMHSA's Center for Mental Health Services and Center for Substance Abuse Treatment.

Years of reliable data and research demonstrate that the most successful intervention to solve chronic homelessness is linking housing to appropriate support services. Current SAMHSA investments in homeless programs are highly effective and cost-efficient. However, funding for SAMHSA homeless programs has remained flat for the past four years, often making it difficult for communities to increase the number of homeless households they are serving with the service dollars. As communities are investing additional housing resources into serving high-need homeless populations, Congress should increase funding for services to help those populations address their long-term health related issues.

Projects for Assistance in Transition from Homelessness (PATH)
We recommend that Congress increase PATH funding to $75 million.

PATH provides funding for essential outreach to homeless people with serious mental illness and helps them navigate both the homeless and mainstream services systems to get the services they need. PATH-supported programs served over 185,000 people through outreach in fiscal year 2014. Of these, 28% were unsheltered at the time they started receiving PATH services. 64% needed mental health services and 52% had co-occurring substance use disorders.

SOAR Capacity Pilot
We recommend that Congress set aside $10 million in PATH funds to establish a pilot program for dedicated SSI/SSDI Outreach, Access, and Recovery (SOAR) funding.

Some of the hardest to engage persons experiencing homelessness often have co-occurring mental illness and substance abuse disorders, and many have experienced homelessness for years. For these chronically homeless individuals it is difficult to break the cycle of homelessness without supportive services coupled with housing supports. The SOAR program seeks out these individuals and helps them gain access to income and health care. Without some type of income housing is often unattainable. The SOAR program helps connect chronically homeless, disabled individuals to income and supportive services that moves them from homelessness, through treatment, and into housing.

While PATH funding provides limited support to the SOAR program by paying a portion of the salaries of workers, with limited funding available, implementing the SOAR program oftentimes becomes one additional thing that workers have to do on top of their regular duties. In addition, SOAR is oftentimes done voluntarily, as administrators are unable to piece together funding to dedicate to SOAR work. Dedicated SOAR funding is imperative to engaging the hardest to reach chronically homeless individuals and providing them the care and supportive services they need to survive.

Community Health Centers and Health Care for the Homeless (HCH) Programs
We recommend providing $7.48 billion for HRSA, including $5.1 billion in funding for health centers, and the extension of current mandatory funding of $3.6 billion for FY 2018

and FY 2019, as requested by the Administration. This would result in $650.76 million for the Health Care for the Homeless (HCH) program.

Homelessness is a significant barrier to good health. On average, homeless persons die 30 years sooner than their housed counterparts. The constant stress of housing instability exasperates health conditions that may otherwise be both preventable and easily treatable. Without housing and proper treatment, simple cuts become infected, routine colds develop into pneumonia, and manageable chronic diseases such as asthma, hypertension, diabetes, and HIV become disabling, life-threatening and costly conditions.

The HCH program is a "special populations" category of health centers that are required to predominately serve persons experiencing homelessness. Projects under the program meet all the same requirements of any other health center with the additional statutory requirement to provide substance abuse services. To address the interconnected health and social problems faced by many homeless individuals and families, HCH projects may also provide mental health services, health education, system navigation, dental services, pediatric and family services, street outreach, housing, employment services, and other support services. Today, there are 268 HCH grantees, at least one in every state, with over 2,500 service sites. In 2014, HCH projects provided care to more than 850,000 patients; 89% were below the Federal Poverty Level and 43% were uninsured.

Runaway and Homeless Youth Program
We recommend providing $165 million for the Runaway and Homeless Youth Act Program.

Unaccompanied homeless youth experience high rates of victimization, exploitation, human trafficking, juvenile justice and child welfare involvement, and detrimental health effects. Developmentally appropriate and readily accessible trauma-informed services are critical to providing safety, health and healing to these young people. HUD will shortly invest $33 million to demonstrate how a comprehensive approach can dramatically reduce youth homelessness. Congress should provide at least $165 million in funding for RHYA programs in FY 2017 to support existing programs and help communities better meet the needs of homeless and runaway youth through youth-specific innovations.

Conclusion
As communities implement plans to end homelessness, work to move people out of institutional care and seek to end the cycle of over using public systems, they are struggling to find funding for the services that vulnerable populations need to maintain housing. The federal investments in mental health services, substance abuse treatment, primary care, youth housing, and case management discussed above will help communities create stable housing programs and change social systems which will end homelessness for millions of Americans.

American Association of Colleges of Nursing

Testimony of the American Association of Colleges of Nursing
Prepared for the U.S. House Appropriations Subcommittee on Labor, Health and Human Services, and Education, and Related Agencies

U.S. Department of Health and Human Services
Health Resources and Services Administration (HRSA)

National Institutes of Health (NIH)
April 15, 2016

Submitted by Deborah Trautman, PhD, RN, FAAN, President and Chief Executive Officer, American Association of Colleges of Nursing

As the national voice for baccalaureate and graduate nursing education, the American Association of Colleges of Nursing (AACN) represents over 780 schools of nursing that educate over 457,000 students and employ more than 18,000 faculty members. Collectively, these institutions prepare our nation's Registered Nurses (RNs), Advanced Practice Registered Nurses (APRNs), nurse faculty members, and nurse scientists.

AACN respectfully requests that the subcommittee invests in America's health by providing **$244 million for HRSA's Nursing Workforce Development programs** (authorized under Title VIII of the Public Health Service Act [42 U.S.C. 296 et seq.]), at least **$34.5 billion for the National Institutes of Health (of which, $157 million is provided for the National Institute of Nursing Research (NINR))**,* and to **provide a discretionary appropriation for the National Health Service Corps (NHSC) in Fiscal Year (FY) 2017**. These programmatic requests will ensure that our nation's nurses are prepared to care for the growing number of patients requiring a complex range of healthcare services.

*The Ad Hoc Group for Medical Research, of which AACN is a member, requests at least $34.5 billion for NIH in FY 2017, and the request level of $157 million for NINR denotes the same percentage increase for NIH applied to NINR.

The Role of Nurses in Our Healthcare System

As integral members of the healthcare team, and as the largest sector of the workforce with over three million licensed providers,[1] nurses collaborate with other professions and disciplines to improve the quality of America's healthcare system and ensure employment of timely and effective services. Nurses serve in a multitude of settings, including hospitals, long-term care facilities, community centers, local and state health departments, schools, workplaces, and patient homes. RNs and APRNs treat and educate patients across the entire life span and ensure individuals follow through with care plans for optimal health outcomes.

It is imperative that individuals seeking to enter the nursing profession have the financial support to pursue advanced education. Federal investments are essential to ensure that a robust workforce of RNs and APRNs are available to provide the care that Americans need now and in the years to come. Moreover, the nursing pipeline will need to supply highly-educated nurses to respond to innovative, team-based delivery models that promote safe, efficient, patient-centered care.

Title VIII Programs Are Improving Healthcare Today and in the Future

For over fifty years, the Nursing Workforce Development programs have helped build the supply and distribution of qualified nurses to meet our nation's healthcare needs. The programs strengthen nursing education at all levels, from entry preparation through graduate study, and provide support to educate nurses who practice in rural and medically underserved communities. Title VIII programs are essential to ensuring that the demand for nursing care is met by supporting future practicing nurses and the faculty who educate them. Moreover, the goals of these programs align with the Institute of Medicine's report, *Future of Nursing: Leading Change, Advancing Health*, which calls for nurses to "achieve higher levels of education and training through an improved education system that promotes seamless academic progression."[2]

Title VIII programs address specific aspects of the nursing workforce and patient populations experiencing high need, such as primary care, diversity in the workforce, and the aging population. The demand for APRNs (which include nurse practitioners (NPs), certified registered

[1] National Council of State Boards of Nursing. (2016). *Active RN Licenses: A profile of nursing licensure in the U.S. as of January 23, 2016.* Retrieved from: https://www.ncsbn.org/6161.htm.

[2] Institute of Medicine. (2010). *Future of Nursing: Leading Change, Advancing Health Report Recommendations.* Retrieved from: http://www.iom.edu/Reports/2010/The-Future-of-Nursing-Leading-Change-Advancing-Health/Recommendations.aspx.

nurse anesthetists (CRNAs), certified nurse-midwives (CNMs), and clinical nurse specialists), necessitates a greater number of nurses with advanced degrees. According to the U.S. Bureau of Labor Statistics, the projected employment of NPs, CRNAs, and CNMs is expected to grow 31% between 2012-2022.[3] APRNs are a real solution to the challenge of employing high-quality providers in primary care and underserved communities. Title VIII programs, such as the Advanced Education Nursing Traineeship (AENT) and Nurse Anesthetist Traineeship (NAT) provide nurses with exposure to populations in need of their care and offer potential future employment opportunities. In academic year 2014-2015, AENT supported 3,008 students, of which 72% were trained in primary care settings.[4] In the same academic year, NAT supported 3,229 students, of which 64% were trained in medically underserved areas.[4]

Ensuring a diverse nursing pipeline that reflects an increasing diverse population is a national priority. The Title VIII Workforce Diversity Grants program specifically targets groups under-represented in nursing by awarding grants and contract opportunities. In academic year 2014-2015, the program supported 13,225 students and aspiring students and partnered with over 900 clinical training sites.[4]

According to the U.S. Census Bureau, as of July 2013, 44.7 million people (14.1% of the nation's population) are over the age of 65, and by 2060, one in four U.S. residents will be 65 years of age or older.[5] The IOM identified that in order to adequately meet the demands of our aging population, our healthcare system must address the severe shortage of geriatric specialists and providers with geriatric skills and the increased demand for chronic care management skills.[2] The Title VIII Comprehensive Geriatric Education program directly addresses those target areas identified by the IOM. In academic year 2014-2015, the program supported 22,743 nurses and health professionals who provide direct care to our nation's elderly patients.[4] In addition, these programs help prepare faculty members and provide continuing education those pursing advanced degrees in geriatric nursing.[4]

---

[3] U.S. Bureau of Labor Statistics. (2014). *Occupational Outlook Handbook. Nurse Anesthetists, Nurse Midwives, and Nurse Practitioners*. Retrieved from: http://www.bls.gov/ooh/healthcare/nurse-anesthetists-nurse-midwives-and-nurse-practitioners.htm.

[4] U.S. Department of Health and Human Services. (2016). *Health Resources and Services Administration Fiscal Year 2016 Justification of Estimates for Appropriations Committees*. Retrieved from: http://hrsa.gov/about/budget/budgetjustification2017.pdf.

[5] United States Census Bureau. (2015). *Older Americans Month: May 2015*. Retrieved from: http://www.census.gov/content/dam/Census/newsroom/facts-for-features/2015/cb15-ff09_older_american_month.pdf

AACN urges the subcommittee to preserve and support increased funding for all six of the Nursing Workforce Development programs including; Advance Education Nursing; Nursing Workforce Diversity; Nurse Education, Practice, Quality, and Retention; NURSE CORPS Loan Repayment and Scholarship Programs; Nurse Faculty Loan Program; and the Comprehensive Geriatric Education. These programs are vital investments to support the supply and distribution of qualified nurses to meet our nation's health care needs.

AACN respectfully requests $244 million for the Title VIII Nursing Workforce Development programs in FY 2017.

National Institute of Nursing Research: Care across the Lifespan

As one of the 27 Institutes and Centers at the National Institutes of Health (NIH), NINR develops knowledge to build the scientific foundation for clinical practice, prevent disease and disability, manage and eliminate symptoms caused by illness, and enhance end-of-life and palliative care.[6] Broadly speaking, these priorities focus on reducing disease and promoting health and wellness across the entire lifespan. Nurse scientists, often working collaboratively with other health professions, generate the evidence that serves at the foundation of the care nurses provide. For over thirty years, NINR has examined ways to improve care models to deliver safe, high-quality, and cost-effective health services to the nation.

In addition, NINR allots a generous portion of its budget towards training new nursing scientists, thus helping to sustain the longevity and success of nursing research. According to 2015-2016 AACN data, there are 5,035 doctoral students pursuing their PhD within AACN member schools, many of whom will also serve as faculty in our nation's nursing schools.[7] NINR training opportunities, such as the National Research Service Awards, helps new nurse researchers conduct independent research and collaborate in interdisciplinary research.[8] These future nurse scientists will help discover new and effective care technologies and methods to improve patient wellness.

[6] National Institute of Nursing Research. (2012). *FAQ*. Retrieved from: https://www.ninr.nih.gov.
[7] American Association of Colleges of Nursing. (2016). *2015-2016 Enrollment and Graduations in Baccalaureate and Graduate Programs in Nursing*. Washington, DC.
[8] National Institute of Nursing Research. (2015) *Extramural Training Opportunities*. Retrieved from: https://www.ninr.nih.gov/training/trainingopportunitiesextramural#.VwvelHpl1CA

AACN respectfully requests at least $34.5 billion for the NIH (and of this, $157 million for the NINR) in FY 2017.

National Health Service Corps: Supporting Providers in our Nation's Areas of Need

According to HRSA, as of December of 2015 there were over 61.2 million individuals living in Health Professional Shortage Areas (HPSAs).[9] A HPSA designation denotes an area that has a shortage of health professionals within primary, dental, or mental health care.[9] The NHSC Scholarship Program and Loan Repayment Program provide financial support to graduate health professions students and providers who are committed to practicing in these health disciplines and within HPSAs. Moreover, the NHSC attracts highly-qualified APRNs to serve in our nation's underserved communities, ensuring necessary care services reach the millions of patients currently living HPSAs. It is imperative that these programs receive an annual discretionary appropriation to ensure stability and more importantly, to ensure those necessary care services are reaching our patients in all corners of the country.

AACN respectfully requests a discretionary appropriation for the NHSC in FY 2017.

Thank you for considering AACN's requests for FY 2017. If you have any questions, or if AACN can be of assistance, please contact AACN's Senior Director of Government Affairs and Health Policy, Dr. Suzanne Miyamoto, at Smiyamoto@aacn.nche.edu or 202-463-6930, ext. 247.

[9] U.S. Health Resources and Services Administration. (2016). *Designated Health Professional Shortage Areas Statistics*. Retrieved from: https://ersrs.hrsa.gov/ReportServer?/HGDW_Reports/BCD_HPSA/BCD_HPSA_SCR50_Qtr_Smry_HTML&rc:Toolbar=false.

NATIONAL CONGRESS OF AMERICAN INDIANS

Subcommittee on Labor, Health and Human Services, and Education, and Related Agencies
House Committee on Appropriations
U.S. Senate
April 15, 2016

Written Testimony for Fiscal Year 2017

EXECUTIVE COMMITTEE

PRESIDENT
Brian Cladoosby
Swinomish Tribe

FIRST VICE-PRESIDENT
Fawn Sharp
Quinault Indian Nation

RECORDING SECRETARY
Aaron Payment
Sault Ste. Marie Tribe of Chippewa Indians of Michigan

TREASURER
W. Ron Allen
Jamestown S'Klallam Tribe

REGIONAL VICE-PRESIDENTS

ALASKA
Jerry Isaac
Native Village of Tanacross

EASTERN OKLAHOMA
Joe Byrd
Cherokee Nation

GREAT PLAINS
Leander McDonald
Spirit Lake Nation

MIDWEST
Roger Rader
Pokagon Band of Potawatomi

NORTHEAST
Lance Gumbs
Shinnecock Indian Nation

NORTHWEST
Mel Sheldon, Jr.
Tulalip Tribes

PACIFIC
Jack Potter, Jr.
Redding Rancheria

ROCKY MOUNTAIN
Darrin Old Coyote
Crow Nation

SOUTHEAST
Larry Townsend
Lumbee Tribe

SOUTHERN PLAINS
Liana Onnen
Prairie Band of Potawatomi Nation

SOUTHWEST
Joe Garcia
Onkay Owingeh Pueblo

WESTERN
Bruce Ignacio
Ute Indian Tribe

EXECUTIVE DIRECTOR
Jacqueline Pata
Tlingit

NCAI HEADQUARTERS
1516 P Street, N.W.
Washington, DC 20005
202.466.7767
202.466.7797 fax
www.ncai.org

The National Congress of American Indians (NCAI) is the intergovernmental body for American Indian and Alaska Native tribal governments. NCAI is the oldest and largest national tribal organization in the United States that is dedicated to protecting the rights of tribal governments to achieve self-determination and self-sufficiency. For over sixty years tribal governments have come together as a representative Congress through NCAI to consider issues of critical importance to tribal governments and endorse consensus policy positions. NCAI appreciates the opportunity to offer the following testimony on tribal programs in the Departments of Labor, Education, and Health and Human Services.

U.S. Department of Health and Human Services:

NCAI supports investments in tribal health and well-being across the Department of Health and Human Services (HHS) agencies.

Substance Abuse Mental Health Services Administration: NCAI appreciates the funding increases made to Tribal Behavioral Health Grants in the FY 2016 appropriations bill. NCAI requests continued funding of at least $30 million, which includes $15 million in the Mental Health appropriation and $15 million in the Substance Abuse Prevention appropriation. These funds are essential in the promotion of mental health and prevent substance activities for high-risk American Indian/Alaska Native (AI/AN) youth and their families.

Administration for Community Living (ACL): Native American Nutrition and Supportive Services: NCAI recommends $31 million for this program. This program provides nutrition and other direct supportive services to American Indian, Alaska Native, and Native Hawaiian elders. These programs help to reduce the need for costly nursing home care by supporting adult day care, meal delivery and transportation.
Head Start: Head Start funds provide early education to over 24,000 Native children. This vital program combines education, health, and family services to model traditional Native education, which accounts for its success rate. NCAI recommends the Subcommittee to provide $9.6 billion total funding for Head Start, which includes Indian Head Start. Head Start has been and continues to play an instrumental role in Native education.

Administration for Children and Families
NCAI supports start-up funding for tribal IV-E programs and improving of tribal access to Promoting Safe and Stable Families.

Start-up funding and increase match for tribal IV-E programs: NCAI urges Congress to improve tribes' capacity to operate title IV-E programs by providing start-up funding and an increased match for tribal IV-E. The President's budget includes a proposal that allows Indian tribes, tribal organizations, or consortia that are approved to operate a title IV-E program to apply for start-up funding to assist with the implementation of the program requirements in title IV-E of the Social Security Act. A second proposal would amend title IV-E to develop the tribal child welfare workforce by increasing the match rate for tribal case work activities and increasing the Federal financial participation to 90 percent for training tribal caseworkers.

Increasing Tribal Access to Promoting Safe and Stable Families (PSSF): NCAI supports an increase of $20 million in the discretionary PSSF appropriation from the FY 2016 enacted level to improve tribal capacity to administer child welfare services. American Indian and Alaska Native children are disproportionately represented at two times their population in state child welfare systems nationally. Among individual state foster care systems they are overrepresented at as much as 10 times their population rate. NCAI urges Congress to help address the disproportionality affecting Native children by investing in tribal child welfare systems.

Many tribes lack infrastructure and stable funding. While tribes may directly administer title IV-E programs, many tribes still need to build their child welfare programs. With this increase, total funding reserved for formula grants for tribes will be $31 million, including $22 million discretionary and $9 million mandatory.

Tribal Court Improvement: A $2.75 million increase is proposed for this program to allow ACF to fund a total of 25 tribal court improvement grants. The expansion of the Tribal Court Improvement Program would continue to strengthen the tribal court's capacity to exercise jurisdiction in Indian Child Welfare Act cases and to adjudicate child welfare cases in tribal court.

Low-Income Home Energy Assistance Program (LIHEAP): Provide $4.7 billion for LIHEAP, with $51 million allocated to tribes and tribal organizations. The LIHEAP is intended to assure that low-income families will not be forced to choose between food and heat. With high unemployment and long-standing barriers to economic development, much of Indian Country cannot afford the rising costs of heat and power. Alaska Native villages are experiencing some of the highest costs for energy with fuel prices recently reaching $7 per gallon. In FY 2011, LIHEAP was appropriated $4.7 billion total, with $51 million allocated to tribes and tribal organizations. Full funding is crucial to address the extreme need for heating assistance in Indian Country. Accordingly, funding for FY 2017 should be $51 million for tribes.

U.S. Department of Education:

Title I Part A Local Education Agency Grants: Title I of the Every Student Succeeds Act (ESSA) provides critical financial assistance to local educational agencies (LEAs) and schools with high percentages of children from low-income families that ensure all children meet challenging state academic standards. Currently, there are over 600,000 Native students across the country with nearly 93 percent of those students attending public schools in rural and urban locations. A drastic increase in funding to counter annual inflation and sequestration, as well as to match the amount appropriated under the American Reinvestment and Recovery Act (ARRA), is necessary to meet

the needs of Native students and students from low-income families. NCAI recommends funding of $25 billion for Title I, Part A.

Impact Aid: Impact Aid provides direct payments to public school districts as reimbursement for the loss of traditional property taxes due to a federal presence or activity, including the existence of an Indian reservation. With nearly 93 percent of Native students enrolled in public schools, Impact Aid provides essential funding for schools serving Native students. Funding for Impact Aid must not be less than this requested amount. Furthermore, Impact Aid should be converted to a forward-funded program to eliminate the need for cost transfers and other funding issues at a later date. NCAI requests the Subcommittee to provide $2 billion in funding for Impact Aid, Title VII funding under the Every Student Succeeds Act.

Title VI-Indian Education:

Grants to Local Education Agencies (Title VI, Part A): Increases are needed as this critical grant funding is designed to supplement the regular school program and assist Native students so they have the opportunity to achieve the same educational standards and attain parity with their non-Native peers. Title VI funds support early-childhood and family programs, academic enrichment programs, curriculum development, professional development, and culturally-related activities. These grants provide much needed resources to Native communities to invest in the success of their students. NCAI recommends funding of $198 million for LEA grants.

Native American and Alaska Native Language Immersion Schools and Programs (Title VI, Part A, Subpart 3): Native American and Alaska Native Language Immersion Schools and Programs would strengthen tribal sovereignty, while protecting the cultural and linguistic heritage of Native students in education systems. In years past, funding for Title VI only reached 500,000 Native students leaving over 100,000 without supplementary academic and cultural programs in their schools. As Native students lag behind their non-Native peers in educational achievement, increased funding is necessary to address this substantial gap. NCAI urges the Subcommittee to fund immersion programs at $6.6 million for FY 2017.

Alaska Native Education Program (Title VI, Part C): This essential program 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. Other eligible activities include professional development for educators, activities carried out through Even Start programs and Head Start programs, family literacy services, and dropout prevention programs. NCAI recommends the Alaska Native Education Equity Assistance Program be funded at $35 million for FY 2017.

Native Hawaiian Education Program (Title VI, Part B): Increases are needed as this critical grant program funds the development of curricula and education programs that address the unique needs of Native Hawaiian students to help bring equity to this Native population. The Native Hawaiian Education Program empowers innovative culturally appropriate programs to enhance the quality of education for Native Hawaiians. These programs strengthen the Native Hawaiian culture and improve educational attainment, both of which are correlated with positive economic outcomes. NCAI recommends funding of $35 million for Native Hawaiian Education Program for FY 2017.

Tribal Colleges and Universities: Supporting Financially Disadvantaged Students: Titles III and V of the Higher Education Act, known as Aid for Institutional Development programs, support institutions with a large proportion of financially disadvantaged students and low cost-per-student expenditures. Tribal Colleges and Universities (TCUs) clearly fit this definition. The nation's 37 TCUs serve Native and non-Native students in some of the most impoverished areas in the nation. Congress recognized the TCUs as emergent institutions, and, as such, authorized a separate section of Title III (Part A, Sec. 316) specifically to address their needs. Additionally, a separate section (Sec. 317) was created to address similar needs of Alaska Native and Native Hawaiian institutions. NCAI urges this Subcommittee to appropriate $60 million ($30 million in discretionary funding and $30 million in mandatory funding) for Title III-A grants under the Higher Education Act for Tribal Colleges and Universities.

Tribally Controlled Post-Secondary Career and Technical Institutions: Section 117 of the Carl Perkins Career and Technical Education Improvement Act authorizes funding for operations at tribally controlled postsecondary career and technical institutions. Vocational education/training programs are very expensive to conduct, but are vital to preparing a future workforce that will operate safely and efficiently contributing greatly to the global economy. Currently, two TCUs participate in this funding program: United Tribes Technical College in Bismarck, North Dakota, and Navajo Technical College in Crownpoint, New Mexico. NCAI recommends $10 million for tribally controlled postsecondary career and technical institutions program funds under the Carl Perkins Career and Technical Education Improvement Act.

Native American-Serving, non-Tribal Institutions (Higher Education Act Title III-F): As the primary federal funding for non-tribal, Native-serving institutions of higher education, the current funding levels are insufficient. With nearly 100 institutions potentially qualifying as Native-serving, non-tribal institutions, this strains the small amount of available funding. Increasing the funding will provide the opportunity for more Native-serving institutions to better serve their students and increase graduation rates among Native students. NCAI urges the Subcommittee to fund $10 million for non-tribal, Native-serving institutions of higher education.

In conclusion, NCAI appreciates the opportunity to share these recommendations with the Subcommittee. The needs in Indian Country are great and we thank this Subcommittee for working to honor the federal Indian trust responsibility.

National Council of State Directors of Adult Education

Testimony of Jeff Carter

Executive Director of the National Council of State Directors of Adult Education submitted to the House Subcommittee on Labor, Health and Human Services, and Education, and Related Agencies Concerning Funding Levels in the Department of Education for Adult Education and Family Literacy

The National Council of State Directors of Adult Education (NCSDAE) appreciates the opportunity to submit testimony about the funding level for Adult Education in the Department of Education's FY 2017 Budget, specifically Title II of the Workforce Innovation and Opportunity Act (WIOA). **NCSDAE believes that funding for WIOA Title II in FY 2017 should be at least $635 million.**

Adult education serves adults, 16 years of age and older, who are no longer in school or are functioning below the high school completion level. Services include teaching foundational skills like reading, math, and English coupled with college and career readiness skills that lead to adult secondary education and the transition to post-secondary education. Public schools, community colleges, and community-based organizations provide programs at the local level.

NCSDAE believes that funding for Adult Education in FY 2017 should be *at least* $635 million, the level authorized in WIOA, which Congress passed less than two years ago, by overwhelmingly bi-partisan votes in both the House (415-6) and Senate (97-3). The law established Adult Education as one of the four key programs in the workforce system because it recognized the crucial role Adult Education plays in educating our population, teaching English and civics, and preparing adults to enter the workforce or improve their employment status. **Such improvements as the law anticipates cannot be fully realized without sufficient resources.**

The president's proposed budget of $606.67 million for adult education for FY 2017 is $28.53 million below Title II's authorized level of $635.20 million. The Adult Education State Grants program would be frozen at $581.96 million, with $69,835 (12%, as authorized under Title II) set aside for the continuation of English Literacy/Civics Education State Grants. National

Leadership Activities would receive $24.71 million — a $11 million increase over the FY 2016 funding level, and $12.71 million over the authorized amount for FY 2017 under Title II, which has a formula cap on National Leadership Activities of 2% of the overall appropriation, not to exceed $15 million.

While Congress provided a welcome increase of $13 million to the State Grants program in the FY 2016 omnibus, the federal investment in the Adult Education State Grants program has largely been on the decline in terms of real dollars since FY 2002. While the president's proposed budget preserves the $13 million increase provided by Congress in the omnibus, that funding level would continue to support just 1.5 million of the 36 million adults who would benefit from these important services—significantly fewer students than the system's highest enrollment year of 2002, when it served almost 2.8 million students. (It is important to note that one million school age children drop out of school each year adding to the number who would benefit from Adult Education.)

We request that Adult Education be funded at the WIOA-authorized level for FY 2017 -- $635.20 million -- and that the amount for National Leadership Activities be allocated in accordance with the statute ($12.70 million), leaving $622.50 million for the Adult Education State Grants program.

The Need

Adult Education State Grants have been essentially flat-funded since FY 2002. Adjusted for inflation, this is a reduction in real dollars of nearly 25%. Enrollment has decreased most sharply among the low-income populations that most need adult education and workforce skills services.

While some adults enrolled in adult education are students seeking their high school diploma or equivalent, a surprisingly large number of American adults who have earned a high school diploma still struggle with basic skills. Twenty percent (20%) of adults with a high school diploma have less-than-basic literacy skills and 35% of adults with a high school degree have less-than-basic numeracy skills. According to a recent study conducted by OECD's Program for International Assessment of Adult Competencies (PIAAC), at least three million low-skilled American adults would like to enroll in Adult Education services, but cannot access a program.

Without access, undereducated, under-prepared adults cannot qualify for jobs with family sustaining incomes that require not only a high school equivalency, but also some college—preferably a one or two year certificate in a high demand occupation.

The Impact of Underinvestment

Significant underinvestment in adult education and workforce skills development is eroding America's global competitiveness. A robust adult education system is essential if we are to achieve our nation's economic goals. It will be impossible to create a workforce skilled enough to compete in the global 21st Century economy if we focus only on secondary schools and postsecondary institutions. Thirty-two (32) states need more adults with college degrees to reach international competitiveness. **States cannot close the gap with traditional college students. They must rely on the re-entry pipeline—getting older adults back into the education system and on track to attaining college degrees.** High schools alone cannot provide business and industry the workers they need. **Most of America's workforce of tomorrow is already in today's workforce. They are beyond the reach of the high schools and postsecondary education. Adult education is the best way to re-engage them.**

Further, the Census Bureau projects that between 2000 and 2015, net international immigration will account for more than half of our nation's population growth, increasing even more the demand for adult English-language programs for adults.

By neglecting the adult population in need of education, we also harm the prospects of the next generation—57% of children whose parents don't have a college education live in low-income families, and are less likely themselves to get a good education qualify for family-sustaining jobs.

A new PIAAC report issued in March 2016, "Skills of U.S. Unemployed, Young, and Older Adults in Sharper Focus," concludes that U.S. adults have, on average, weaker numeracy and digital problem-solving skills relative to adults in 17 other developed countries, and their literacy skills are only average. Marc Tucker, president and CEO of the National Center for Education and the Economy, told the Wall Street Journal that this new report shows that "American workers, once the best educated in the world are now among the least well-educated in the industrialized world."

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

In addition, according to a 2007 report by the National Commission on Adult Literacy, the U.S. could save up to $1.4 billion per year in reduced costs from crime if the high school completion rate increased by just 1% for all men aged 20 to 60. Improving adult literacy could also save up to $238 billion annually in health care costs, and overall lifetime earnings would increase up to $191 billion if all adults aged 25-64 without a high school diploma acquired a high school diploma or equivalent.

FY 2017 Funding Request

The need for an even greater long-term investment is clear, but at a minimum, recognizing the budgetary restraints that currently exist, the State Directors strongly urge you to fund Title II of WIOA at the $635 million level authorized in the legislation. We also recommend that the $11 million increase that the President requests for National Leadership Programs instead be allocated to the State Grant program to help all states implement WIOA.

Other nations are fast outstripping America in boosting the educational levels of their young and working age adults. They are showing consistent decade-to-decade progress in enhancing the education levels of their adult populations, while the U.S. is losing ground. If Americans are to embark or continue on pathways that lead to good jobs and good wages, we *must* invest adequately in our Adult Education system to remain economically competitive.

Please contact: Jeff Carter, Executive Director, at jcarter@ncsdae.org or Gene Sofer, Director of Government Relations, at: eugenesofer@gmail.com

Testimony of the American College of Preventive Medicine
Concerning Fiscal Year 2017 HRSA Appropriations

Submitted for the Record to the House Appropriations Subcommittee on Labor, Health and Human Services, Education, and Related Agencies – April 15, 2016

The American College of Preventive Medicine (ACPM) urges the House Labor, Health and Human Services, Education, and Related Agencies Appropriations Subcommittee to reaffirm its support for training preventive medicine physicians by providing **$11 million in FY2017 to the Health Resources and Services Administration's (HRSA) public health and preventive medicine line-item contained within the public health workforce development program.** ACPM also supports the recommendation of the Health Professions and Nursing Education Coalition of restoring HRSA's discretionary budget authority to the FY2010 level of $7.48 billion.

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

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

In fact, preventive medicine is the only one of the 24 medical specialties recognized by the American Board of Medical Specialties ***that requires and provides training in both clinical and population-based medicine***. Preventive medicine residency training programs provide a blueprint on how to train our future physician workforce; physicians trained to provide individual patient care needs as well as practice at the community and population level to identify and treat the social determinants of health. Preventive medicine physicians have the training and expertise

to advance the population health outcomes that public and private payers are increasingly promoting to their providers. These physicians have a strong focus on quality care improvement and ***are at the forefront of efforts to integrate primary care and public health***.

According to the Health Resources and Services Administration (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 2014 Physician Specialty Data Book released by the Association of American Medical Colleges, preventive medicine had the biggest decrease (-29%) in the number of first-year ACGME residents and fellows between 2008 and 2013. This decrease represents a worsening trend in the number of preventive medicine residents and is not due to a lack of interest or need but is due to a lack of funding. 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. 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. 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, preventive medicine training programs and their residents are in need of enhanced federal support.

Currently, residency programs scramble to patch together funding packages for their residents. Limited stipend support has made it difficult for programs to attract and retain high-quality applicants. 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 a small number of preventive medicine residency programs, as it represents the largest federal funding source for these programs.

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

- ***Thirty-five percent*** of HRSA-supported preventive medicine graduates practice in medically underserved communities, a rate of almost ***3.5 times*** the average for all health professionals. These physicians are meeting a critical need in these underserved communities.

- ***Nearly one in five*** preventive medicine residents funded through HRSA programs are under-represented minorities, which is almost twice the average of minority representation among all health professionals.
- ***Fourteen percent*** of all preventive medicine residents are under-represented minorities, the largest proportion of any medical specialty.

In addition to training under-represented minorities and generating 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. 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. ACPM applauds the initiation of programs such as Care Coordination Organizations that take this broad view of the determinants of chronic disease. However, 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.

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. 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 by providing **$11 million in FY2017 for preventive medicine residency training under the public health and preventive medicine line-item at HRSA.**

Testimony of Thomas A. Teasdale, DrPH, MPH Director
Oklahoma Geriatric Education Center (OkGEC)
Professor and Chair, Department of Health Promotion Sciences
University of Oklahoma College of Public Health
PO Box 26901
Oklahoma City, OK 73126
405-271-2017 x46753
thomas-teasdale@ouhsc.edu
www.coph.ouhsc.edu/departments/hps

And

Jan Busby-Whitehead, MD
Mary and Thomas Hudson Distinguished Professor of Medicine
Chief, Division of Geriatric Medicine, Department of Medicine
Director, Center for Aging and Health
University of North Carolina School of Medicine
5003 Old Clinic Building
Chapel Hill, NC 27599
919 445-6774
Jan_Busby-Whitehead@med.unc.edu

Submitted for the Record to the House Appropriations Subcommittee on Labor, Health and Human Services, Education, and Related Agencies – Addressing the Health Resources and Services Administration (HRSA)

As a board member and president of the National Association for Geriatric Education (NAGE), we are pleased to submit this statement for the record recommending at least **$44.7 million in Fiscal Year 2017 to support geriatrics programs** under the ***Geriatrics Workforce Enhancement Program (GWEP)*** administered by the Health Resources and Services Administration (HRSA). We thank you for your past support.

Last year, the Health Resources and Services Administration (HRSA) combined the geriatric education programs in Titles VII and VIII along with portions of the Alzheimer's Disease Prevention, Education, and Outreach Program to establish the Geriatrics Workforce

Enhancement Program (GWEP). The GWEP is now the only federal program designed to improve health care quality and safety for older adults, plus reduce associated costs of care through appropriate training of health care professionals, caregivers, and direct service workers. Proven results from activities under the predecessor programs include an important increase in the number of teaching faculty with geriatrics expertise in a variety of disciplines, plus thousands of health care providers and family caregivers better prepared to support older Americans. Therefore, NAGE requests a total of at least $44.7 million for these programs which are critical to caring for the elderly population. They were funded at $38.7 million in FY 2016.

We recognize that the Subcommittee faces difficult decisions in a constrained budget environment, but we believe that a continued commitment to geriatric education programs that help the nation's health professions better serve the older and disabled population should remain a top priority. The nation faces a shortage of geriatric health professionals. Every day in America 10,000 more persons reach 65 years of age. There simply are not enough geriatricians, geriatric nurse practitioners and other health professionals trained in geriatrics needed to care for this rapidly increasing older population. Too often, the result is expensive walk-in care. We believe that funding for GWEP-based geriatric education supports your important work to establish a sustainable future for the nation's health care and Social Security systems by ensuring that (a) health care specialists trained in geriatric care do not become a rare and expensive resource and (b) direct service workers and family caregivers are prepared to support a lower cost, independent lifestyle for community residing elders.

Under the new structure of GWEP, forty newly funded education centers continue much of the work conducted by Geriatric Education Centers (GEC), Comprehensive Geriatric

Education Programs (CGEP), Geriatric Academic Career Awards (GACA), and Geriatric Training for Physicians, Dentists and Behavioral and Mental Health Providers (GTPD) awards. A primary purpose of these GWEP centers is to continue training health care professions faculty, students, and field practitioners in interprofessional diagnosis, management and prevention of disease, disability, and other chronic health problems of the elderly.

Although baseline data for the new program will be set to FY 2015, it will not be reported until the FY 2018 budget. However, HRSA's FY2016 Justification of Estimates for Appropriations Committees notes that for the 2014-2015 reporting year, these programs accomplished an extraordinary amount of work:

- GEC programs provided over 2,800 unique continuing education courses to over 150,900 faculty members and practicing providers, exceeding the program's performance goals again. GEC grantees offered training at primary care settings and/or in medically underserved communities, and many of the courses focused on Alzheimer's disease treatment and education.
- Grantees also provided more than 39,100 clinical training experiences for health care professions students at more than 1,770 health care delivery sites, with 32 percent located in medically-underserved communities.
- GEC grantees supported the training of faculty in geriatrics with more than 2,900 structured faculty development programs with more than 13,200 faculty members receiving training in geriatric-related topics.

New GWEP awardees received expanded authorization to provide to family caregivers

and direct service workers instruction on prominent issues in the care of older adults, such as Alzheimer's disease and other dementias, palliative care, self-care, chronic disease self-management, falls, and maintaining independence, among others.

Geriatric education programs have improved the supply, distribution, diversity, capabilities, and quality of health care professionals who care for our nation's growing older adult population, including the underserved and minorities. We need your continued support for geriatric programs to adequately prepare the next generation of health professionals for the rapidly changing and emerging needs of the growing and aging population.

On behalf of NAGE and those who have benefitted in Oklahoma and North Carolina and from our colleagues around the country, thank you for this opportunity to share our request for support for these important programs. We ask that you thoughtfully consider our request for funding in FY 2017.

NAGE is a non-profit membership organization representing Geriatrics Workforce Enhancement Programs, Geriatric Education Centers, and other programs that provide education and training to health professionals in the areas of geriatrics and gerontology.

Harm Reduction Coalition FY 2017 Appropriations Request for Overdose Prevention

My name is Daniel Raymond, and I am the Policy Director for the Harm Reduction Coalition. I appreciate the opportunity to submit this testimony to Harm Reduction Coalition recommends prioritizing funding needs under SAMHSA, HRSA and CDC towards three key strategies which address overdose risk and mortality: medication-assisted treatment, overdose education and naloxone distribution, and syringe exchange programs. Specifically, we are proposing $20 million to SAMHSA and $10 million to HRSA for overdose prevention, and $15 million to CDC to support syringe exchange programs. We also support Administration requests to expand access to medication-assisted treatment for opioid use disorders.

Opioid overdose fatality is the leading cause of accidental death in the United States and has been declared an epidemic by the Centers for Disease Control and Prevention (CDC). According to CDC data, overdose deaths involving opioids – including prescription painkillers and heroin – claimed 28,647 lives in 2014. This figure represents a 14% increase in age-adjusted overdose death rates since 2013. Increased mortality was driven by a dramatic rise in heroin overdose deaths, with heroin overdose death rates more than tripling since 2010, accompanied by a surge in deaths involving illicit fentanyl, a synthetic opioid increasingly combined with – or even sold as – heroin. These high rates of overdose will persist as long as the two most proven tools to prevent overdose deaths – medication-assisted treatment for opioid use disorders, and the overdose reversal drug naloxone – remain starkly underutilized and difficult to access.

Medication-assisted treatment

Medication-assisted treatment (involving methadone, buprenorphine, or Vivitrol, accompanied by counseling and support) is the ***most effective means of facilitating recovery from opioid use disorders***, and use of medication improves retention in treatment. Moreover, evidence shows that use of medication-assisted treatment reduces overdose by 50% compared to treatment without medication. However, the majority of people with opioid use disorders do not have access to medication-assisted treatment: 90% of U.S. counties do not have a methadone clinic, and only 32,000 doctors are waivered to prescribe buprenorphine, leaving 43% of U.S. counties without prescriber capacity.

Overdose education and naloxone distribution

Overdose prevention education and training programs that distribute the FDA-approved, opioid rescue medication naloxone have been ***proven to significantly reduce mortality***. When administered in a timely fashion, naloxone can reverse an opioid overdose; however, tragically it is not yet neither utilized broadly nor widely available in many parts of the country. In response to the opioid overdose epidemic, over 40 states and numerous communities and have taken action to make naloxone available within their jurisdictions. CDC recently reported that 150,000 community members have been trained on overdose prevention and provided with naloxone over the last 20 years, and of those over 26,000 successful overdose reversals have

Harm Reduction Coalition FY 2017 Appropriations Request for Overdose Prevention

been reported by laypersons.[1] However resources to support overdose education and naloxone distribution are still scarce. If naloxone was more accessible and overdose education and awareness efforts were expanded, countless lives could be saved.

Harm Reduction Coalition believes that meaningful access to naloxone requires a four-pronged strategy to achieve a measurable impact on opioid overdose mortality:

1. Support for community-based overdose education and naloxone distribution (OEND) programs and initiatives training and equipping laypersons (family, friends, and people at risk of overdose) with naloxone
2. Promoting and incentivizing health care providers to prescribe naloxone to at-risk patients and their caregivers
3. Advancing innovative models for pharmacy access to naloxone through models including standing orders and collaborative practice agreements
4. Ensuring that first responders, including law enforcement officers, are trained and equipped with naloxone

No single strategy will have a sufficiently broad population-level impact on opioid overdose mortality. ***However, the strongest available evidence suggests that direct support for increasing access to medication-assisted treatment and for community-based OEND programs must be a cornerstone of scale-up and expansion efforts.***

Syringe exchange programs

Syringe exchange programs operate on the frontlines of the opioid and heroin crisis, and pioneered the use of naloxone outside of medical settings. Syringe exchange programs are effective outreach and engagement strategies that provide early intervention to people who inject drugs, linking them to health care and drug treatment. In recent years, new syringe exchange programs have emerged in several communities hard hit by the opioid and heroin epidemic, including in Indiana, Kentucky, Ohio, and West Virginia. These and other communities are grappling with the health and social consequences of increased injection drug use, including rising hepatitis C and hepatitis B infections and an HIV outbreak in Indiana.

Syringe exchange programs operate ***on the frontlines of community-based efforts to reach and assist people at risk of opioid overdose***. These programs are highly effective in engaging and supporting people who use drugs and their communities on overdose education and naloxone distribution, and work to link people struggling with substance use disorders to effective treatment programs, including medication-assisted treatment. In FY 2016, Congress modified provisions to allow more flexibility in use of federal funding to support syringe exchange programs in communities experiencing or at risk of an increase in hepatitis C cases or an HIV outbreak. Congress maintained a restriction prohibiting use of federal funds for the purchase of

[1] Wheeler E, Davidson PJ, Jones TS, Irwin KS. Community-based opioid overdose prevention programs providing naloxone—United States, 2010. Morb Mortal Wkly Rep. 2012; 61(6):101-105.

syringes, but allowed for federal funding to support counseling, education, outreach and other services. Harm Reduction Coalition advocated for and supports the revised federal funding policy.

HHS recently released implementation guidance on use of federal funds to support aspects of syringe exchange programs allowable under the provisions of the FY 2016 Omnibus, and operating in accordance with state and local law. Harm Reduction Coalition's work with these new and emerging syringe exchange programs in high-need areas has convinced us that Congress should appropriate funding in FY 2017 to ensure that these programs have resources to prevent disease transmission, provide overdose education and naloxone distribution, and connect people who use drugs to treatment and health care.

Recommendations for FY 2017

Harm Reduction Coalition recommends that the Subcommittee consider the following investments:

Substance Abuse and Mental Health Services Administration (SAMHSA)

Grants to Prevent Prescription Drug/Opioid Overdose Related Deaths (Center for Substance Abuse Prevention, Programs of Regional and National Significance). Harm Reduction Coalition proposes an increase of $8 million over FY 2016 levels to provide support to additional states for this critical overdose prevention program.

FY 2016 enacted	FY 2017 President's request	Harm Reduction Coalition request
$12,000,000	$12,000,000	$20,000,000 (+$8 million)

Health Resources and Services Administration (HRSA)

Rural Opioid Overdose Reversal Grant Program (ROOR – Office of Rural Health Policy). These funds would support rural communities in addressing opioid misuse and overdose through education and prevention, training of health care professionals, emergency transport, treatment referrals and care coordination, and naloxone purchase.

FY 2016 enacted	FY 2017 President's request	Harm Reduction Coalition request
N/A	$10,000,000	$10,000,000

Centers for Disease Control and Prevention (CDC)

Grants to Support Syringe Exchange Programs (Division of Viral Hepatitis). Harm Reduction Coalition proposes additional funding on top of any increases to core Division of Viral Hepatitis for targeted support to syringe exchange programs.

Proposed language:

Harm Reduction Coalition FY 2017 Appropriations Request for Overdose Prevention

Grants may be awarded to State, local and tribal governments and community-based organizations to support syringe exchange programs. Funds may be used to carry out programs, including through providing outreach, counseling, health education, case management, syringe disposal, and other program components in accordance with allowable use of funds. Funds may also be used to provide technical assistance, including training and capacity-building, to assist the development and implementation of syringe exchange programs. At least 15 percent of grants shall be made to syringe exchange programs that have been in operation for less than 3 years.

FY 2016 enacted	FY 2017 President's request	Harm Reduction Coalition request
N/A	N/A	$15,000,000

Harm Reduction Coalition supports the following Administration requests addressing medication-assisted treatment under SAMHSA:

$50.1 million (+$25.1 million over FY 2016) for Medication-Assisted Treatment for Prescription Drug and Opioid Addiction (MAT PDOA – Center for Substance Abuse Treatment, Programs of Regional and National Significance)

$10 million for Buprenorphine-Prescribing Authority Demonstration (Center for Substance Abuse Treatment, Programs of Regional and National Significance)

In addition, Harm Reduction Coalition strongly supports the Administration's request for $1 billion over FY 2017 and FY 2018 to expand access to treatment for opioid use disorders. This represents a critical investment in treatment capacity at a pivotal moment in the opioid epidemic. While the Administration requested these monies as mandatory funding, Harm Reduction Coalition does not have a position on whether these funds should be discretionary or mandatory. However, we agree with the Administration that a substantive and targeted investment is critical at this juncture, and endorse the proposed approach to allocate the bulk of these funds through new State Targeted Response Cooperative Agreements, with the remaining dollars supporting workforce development and cohort monitoring and evaluation of medication-assisted treatment expansion and outcomes.

We thank you again for your consideration of our testimony and for the subcommittee's previous support for these priorities in FY 2016. Please do not hesitate to contact us if you have any questions.

Daniel Raymond, Policy Director, Harm Reduction Coalition
22 West 27th Street, 5th Floor
New York, NY 10001
raymond@harmreduction.org
212-377-9121

Testimony Submitted by:

Carlo Di Lorenzo, MD
Nationwide Children's Hospital, Columbus, OH
President, North American Society for Pediatric Gastroenterology, Hepatology and Nutrition

Benjamin Gold, MD,
Children's Center for Digestive Healthcare, Atlanta, GA
Member, North American Society for Pediatric Gastroenterology, Hepatology and Nutrition
Public Affairs and Advocacy Committee

Eric Zuckerman, DO
Bloomfield Hill, MI
Board Chairman, Pediatric IBD Foundation

Concerning the
National Institutes of Health and Food and Drug Administration FY 2017 Appropriations

Submitted for the Record to the House Appropriations Subcommittee on
Labor, Health and Human Services, Education, and Related Agencies – April 15, 2016

We are pleased to offer testimony on the nced for a public/private safety registry for pediatric patients with inflammatory bowel disease (IBD). **Specifically, we request on behalf of the North American Society for Pediatric Gastroenterology, Hepatology and Nutrition (NASPGHAN), the Pediatric IBD Foundation, and the thousands of children with IBD Subcommittee consideration of the following report language to the Fiscal Year 2017 Labor, Health and Human Services, Education and Related Agencies Appropriations bill**:

Pediatric IBD Safety Registry: The vast majority (an estimated 80 percent) of medications prescribed by physicians to treat children with inflammatory bowel disease (IBD) are prescribed "off-label" without any mechanism to monitor safety. The Committee recognizes the need for a national pediatric IBD population-based database to capture information on evidence-based health outcomes related to specific therapies and interventions, including concomitant medications and adverse events, and to make data accessible to physicians, patients, industry, researchers, and federal agencies. The Secretary, acting through the National Institutes of Health, in consultation with the Food and Drug Administration, is encouraged to enter into cooperative agreements with public or private entities for the collection, analysis and reporting of data on pediatric IBD.

Prevalence of Inflammatory Bowel Disease

An estimated 1.6 million Americans are living with IBD (Crohn's disease and ulcerative colitis), with nearly one in four patients diagnosed under 20 years of age. IBD is a chronic inflammatory disorder of the intestines that does not have an identifiable cause (such as infection). Pediatric IBD causes the immune system to become inappropriately active, causing injury to the intestines. IBD does not have a medical cure but can be managed effectively through medication or other treatments. When IBD is not effectively managed, children do not grow normally because of a lack of absorption of nutrients. Many suffer constant intestinal pain causing them to miss school, have chronic diarrhea, multiple surgeries and, in some instances, wear colostomy bags.

Treating Inflammatory Bowel Disease

Treatment of a child with active Crohn's disease typically involves an induction regimen that includes a potent therapy with a rapid onset of action. If a remission is achieved, the patient can be transitioned to a maintenance regimen, typically involving medications with a slower onset of action and fewer side effects. The selection of drugs for induction and maintenance depend on age, disease severity, location, and clinical course – called the disease phenotype. In general, very young children with IBD are more likely to have severe or refractory disease, and to have an identifiable genetic cause of the disease (monogenic IBD).

Specific recommendations based on the severity and location of a patient's disease and his or her response to treatment are discussed below.

The ideal goal of treatment is clinical and laboratory remission with mucosal healing, not just symptomatic improvement. However, achieving this goal must be balanced against the risks of IBD therapies. Patients who achieve clinical, laboratory, and endoscopic remission may have better long-term outcomes. Optimal care therefore typically includes one of the following approaches:

- Accelerated *"step-up"* therapy for most patients – Initiate treatment with the least potent drug predicted to be effective, promptly step up therapy to more potent drug if response is incomplete.
- *"Top-down"* therapy for selected high-risk patients and often minority children – Early treatment with a highly potent immunosuppressant (e.g., anti-tumor necrosis factor antibody) for patients with high risks of complicated disease.

With either of these approaches, close monitoring of patients is important to assess for remission (including upper endoscopy and colonoscopy to assess mucosal healing) and to monitor for drug toxicities.

Why a Pediatric IBD Registry is Needed

There are many pediatric diseases and conditions for which great benefit could be derived through coordinated data collection. However, we believe the creation of a pediatric IBD registry, which could serve as a model for other condition-based registries, should be more immediately supported by Congress for the following reasons:

Monitoring the Safety of Off-Label Prescribing — When medications are prescribed for the treatment of IBD in children, the vast majority of these medications (an estimated 80 percent) are not approved by the Food and Drug Administration (FDA) for the indication at the time they are given — meaning, they are not approved by the FDA for use in children and are therefore used "off-label." Medications used to treat IBD are first approved in adults and approval for children may come many years later, if at all, for a variety of reasons which we believe must also be addressed by Congress and the FDA. When medications, often found to be highly effective, are prescribed off-label to children, there is no mechanism to monitor safety, including potential side-effects and contra-indications. For example, a medication approved for treatment of Crohn's disease in adults was recently found to cause a rare but fatal lymphoma in boys who received the medication in combination with another Crohn's treatment. A national registry might have identified this problem much earlier.

Expediting the Approval of Drugs for Pediatric Indications — When medications are prescribed off-label, such is the case with medications to treat pediatric IBD, families frequently incur significant out-of-pocket costs. This is because insurers will not cover medications for indications that are not FDA-approved, even though they are prescribed by physicians and are essential to properly and effectively treat these children, for whom there are few FDA-approved options. A pediatric IBD registry would help expedite drug approvals and encourage drug companies to pursue pediatric indications for FDA-approved drugs by allowing them to access a central data repository rather than establishing cost-prohibitive, proprietary, drug-specific registries for safety monitoring.

Moreover, a registry would greatly enhance global pediatric drug development so medications that carry serious side-effects to treat IBD disease can be avoided and prescribed in more thoughtful evidence-based ways or replaced with better therapies.

Informing Physician Decision-Making — A public-private pediatric IBD registry would be accessible to physicians and patients to aid in treatment decision-making. The need for better data to inform treatment decision-making is of particularly importance when caring for minority populations.

Recent epidemiologic studies describe incidence rates of IBD among African American children have approached and even surpassed those in Caucasians. Furthermore, studies have shown that African American children are diagnosed later, when compared to Caucasian children. This could be for a variety of reasons, although it is speculated that the older age of IBD diagnosis among African American children may be due in part to a low index of suspicion for IBD in minority children among medical providers because IBD has traditionally been viewed as a disease of Caucasians and adults. Furthermore, under-represented minorities often have decreased access to medical care or different patterns of health care seeking behavior thereby leading to much longer delays in diagnosis of IBD in African American children than in Caucasian children and, more importantly, the initiation of critically needed IBD therapy.

Studies continue to show that the disease natural history in African American children is more aggressive, prone to more complications, and requires more interventions, including more powerful medications (i.e., biologics) at earlier stages of the disease after initial diagnosis (i.e., top down therapy). *Top-down* therapy (starting with an immune system suppressing biologic) has also been shown to be more commonly employed in African American pediatric populations with IBD, thus putting these children even more at risk for long-term use of these medications. Additionally, reporting adverse effects and safety monitoring is presently voluntary in the United States — a factor which further contributes to the difficulties facing underserved populations.

IBD in minority populations — African American, Hispanic, African Caribbean — is clearly and substantially increasing in its frequency, and, represents a more aggressive type of IBD. Therefore, it is paramount that a mechanism be in place to monitor safety of the medications used to treat children with IBD, including minority populations.

Maintaining a Central IBD Data Repository — The goal of the aforementioned report language is the creation of a central data repository, which would supplement proprietary, drug-specific registries. Children being treated with IBD medications benefit from FDA-mandated registries, but these registries are often single product and proprietary. Since children are often on multiple products, these registries do not monitor the safety of drug interactions. In addition, most pediatric IBD therapies (approximately 80 percent) are off-label and manufacturers are not required to collect data on off-label use. Furthermore, significant safety data captured on a competitor's medication may not be made public, and these registries lack uniformity of data collection.

Building on Previous Federal Investments — We envision that existing IBD registries would share data points with the public IBD registry which would connect to an existing registry for pediatric rheumatology (CARRA — Childhood Arthritis and Rheumatoid Research Alliance). Connection to the CARRA registry would benefit both pediatric IBD and rheumatology patients because these auto-immune diseases are often treated with the same medications. CARRA was started with a $7.5 million grant to the National Institutes of Health (NIH) in 2009 as a result of funding through the American Recovery and Reinvestment Act. Building on this federally-funded registry would encourage data sharing, extend the government's return on investment, and allow federal regulators and researchers to access data without having to rely on proprietary registries.

Presently CARRA is the only registry that meets federal data sharing requirements per 21CFR-11. We appreciate the interest by many in Congress of a post-marketing data sharing system that could facilitate drug approval for treating rare diseases like pediatric IBD, particularly in diseases where many products are used off-label, thus relieving manufacturers from the obligation of collecting data. Fulfilling the vision of such a post-marketing data sharing system would require each component (i.e., each registry) to meet compliance with 21CFR-11. We therefore believe that the development of a pediatric IBD registry that meets 21CFR-11

requirements and its interconnectivity with the CARRA registry, which already meets these requirements, would offer an excellent demonstration of registry interconnectivity.

Conclusion

A number of organizations have previously joined NASPGHAN and the Pediatric IBD Foundation in calling for a pediatric IBD registry, including the American Medical Association, the American Academy of Pediatrics and the American Gastroenterological Association.[1] We believe report language specifying the need for a pediatric IBD registry is necessary for the initiation of a public-private partnership. Indeed, we believe this language provides the flexibility to the NIH and the FDA to initiate collaborative arrangements with other public and private entities as they did with the CARRA registry, which is an independent 501(c)(3). In this way, the registry is supported with a minimal outlay of federal resources.

On behalf of the thousands of children with IBD, their families, and pediatric gastroenterologists, we thank you for your consideration of our request.

About NASPGHAN:

NASPGHAN, founded in 1972, is the only society in North America and the largest in the world, dedicated to serving the Pediatric Gastroenterology and nutrition communities. NASPGHAN was established to advance the understanding of the normal development and physiology of diseases of the gastrointestinal tract and liver in infants, children, and adolescents, and to foster the dissemination of this knowledge through scientific meetings, professional education, public education, and interaction with other organizations concerned with Pediatric Gastroenterology and nutrition.

About the Pediatric IBD Foundation:

The Pediatric IBD Foundation began in 2009 by parents dedicated to improving the care of children with Crohn's disease and colitis through research, education and advocacy. With philanthropic support from grateful families, the Foundation has brought regulators, (NIH, FDA, EMA), industry and researchers together to help streamline the pediatric drug approval process and safety monitoring of IBD medications. The Foundation supports the oldest and one of the largest biorepositories that supports studies of genetics and microbes that appear to trigger these diseases. We hope that this new knowledge will lead to better diagnostic tests and improved therapies. To communicate this information and support families with information, the Foundation has created a web site that is focused on the needs of children and adolescents with IBD.

[1] Letter to Sen. Llamar Alexander and Sen. Patty Murray, September 9, 2015.

Testimony of Stephen C. Shannon, DO, MPH
President and Chief Executive Officer
American Association of Colleges of Osteopathic Medicine

Concerning the Department of
Health and Human Services Appropriations for Fiscal Year 2017
Submitted for the Record to the House Appropriations Subcommittee on Labor, Health and Human Services, Education, and Related Agencies
April 15, 2016

The American Association of Colleges of Osteopathic Medicine (AACOM) strongly supports restoring funding for discretionary Health Resources and Services Administration (HRSA) programs to $7.48 billion; funding for key priorities in HRSA's Title VII programs under the Public Health Service Act [$59 million for the Primary Care Training and Enhancement (PCTE) Program; $4 million for the Rural Physician Training Grants; $25 million for the Centers of Excellence (COE); $20 million for the Health Careers Opportunity Program (HCOP); $49.1 million for the Scholarships for Disadvantaged Students (SDS) Program; $35 million for the Geriatrics Education Centers (GECs); and $40 million for the Area Health Education Centers (AHECs)]; $527 million in mandatory funding for the Teaching Health Center Graduate Medical Education (THCGME) Program; funding for the National Health Service Corps (NHSC) through the annual appropriations process to create stability and sustainability for the Program; $34.5 billion for the National Institutes of Health (NIH); and $364 million in base discretionary funding for the Agency for Healthcare Research and Quality (AHRQ).

AACOM represents the 31 accredited colleges of osteopathic medicine in the United States.

These colleges are accredited to deliver instruction at 46 teaching locations in 31 states. In the 2015-16 academic year, these colleges are educating over 26,100 future physicians – more than 20 percent of new U.S. medical students.

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 health care workforce, acting as an essential part of the health care safety net and filling the gaps in the supply of health professionals not met by traditional market forces. Title VII programs are the only federal programs designed to train primary care professionals in interdisciplinary settings to meet the needs of special and underserved populations, as well as increase minority representation in the health care workforce.

As the demand for health professionals increases in the face of impending shortages, combined with faculty shortages across health professions disciplines, racial and ethnic disparities in health care, a growing, aging population, and the anticipated demand for increased access to care, these needs strain an already fragile health care system. AACOM appreciates the investments that have been made in these programs, and we urge the Subcommittee for inclusion and/or continued support for the following programs: **the PCTE Program, the Rural Physician Training Grants, the COE, the HCOP, the SDS Program, the GECs, and the AHECs.**

The **PCTE Program** provides funding to support awards to primary care professionals through grants to hospitals, medical schools, and other entities. **AACOM supports a request of $59 million to allow for a new FY17 competitive grant cycle for the PCTE Program's physician training and development.**

The **Rural Physician Training Grants** will help rural-focused training programs recruit and graduate students most likely to practice medicine in underserved rural communities. Health

professions workforce shortages are exacerbated in rural areas, where communities struggle to attract and maintain well-trained providers. According to HRSA, approximately 65 percent of primary care health professional shortage areas are rural. **AACOM supports the inclusion of $4 million for the Rural Physician Training Grants.**

The **COE Program** is integral to increasing the number of minority youth who pursue careers in the health professions. **AACOM supports $25 million for the COE Program.**

The **HCOP Program** provides students from disadvantaged backgrounds with the opportunity to develop the skills needed to successfully compete, enter, and graduate from health professions schools. **AACOM supports an appropriation of $20 million for HCOP.**

The **SDS Program** provides scholarships to health professions students from disadvantaged backgrounds with financial need, many of whom are underrepresented minorities. **AACOM supports increased funding in the President's FY17 budget of $49.1 million for the SDS Program.**

GECs are collaborative arrangements between health professions schools and health care facilities that provide training between health professions schools and health care facilities that provide the training of health professions students, faculty, and practitioners in the diagnosis, treatment, and prevention of disease, disability, and other health issues. **AACOM supports $35 million for the GECs.**

The **AHEC Program** provides funding for interdisciplinary, community-based, primary care training programs. Through a collaboration of medical schools and academic centers, a network of community-based leaders work to improve the distribution, diversity, supply, and quality of health personnel, particularly primary care personnel in the health care services delivery system, specifically in rural and underserved areas. **AACOM supports an appropriation of $40**

million for the AHEC Program in FY17 and strongly opposes the elimination of this vital program in the President's FY17 budget.

AACOM continues to strongly support the long-term sustainment of the **THCGME Program**, which provides funding to support primary care medical and dental residents training in community based settings. THCs currently train more than 690 medical and dental residents and are caring for more than half a million patients in underserved rural and urban communities. This program will also provide long-term benefits. According to HRSA, physicians who train in THCs are three times more likely to work in such centers and more than twice as likely to work in underserved areas as physicians who train in other settings. **AACOM supports the President's FY17 budget request for the THCGME Program of $527 million in mandatory funding through FY18-FY20. We will continue to work with Congress to support a sustainable and viable funding mechanism for the continuation of this successful program.**

The **NHSC** supports physicians and other health professionals who practice in health professional shortage areas across the U.S. In FY15, the NHSC had over 9600 primary care clinicians providing health care services. The NHSC projects that a field strength of more than 15,000 primary care clinicians will be in health professional shortage areas in FY17. In addition, more than 1200 students, residents, and health providers receive scholarships or participate in the NHSC Loan Repayment Program or Student to Service Loan Repayment Program to prepare to practice. **While we were pleased to see a two-year extension of this program in the *Medicare Access and CHIP Reauthorization Act of 2015* (PL: 114-10) for FY16 and FY17, the appropriation committees retain primary responsibility for funding the administrative functions of the NHSC and for avoiding lapses in future years. Therefore, AACOM supports the stability and sustainability of this critical program by requesting that the Subcommittee provide a discretionary appropriation for the NHSC Program.**

Research funded by the **NIH** leads to important medical discoveries regarding the causes, treatments, and cures for common and rare diseases, as well as disease prevention. These efforts improve our nation's health and save lives. To maintain a robust research agenda, further investment will be needed. **AACOM supports an appropriation of $34.5 billion for NIH in FY17, which accounts for inflation associated with biomedical research plus 5%.**

AHRQ supports research to improve health care quality, reduce costs, advance patient safety, decrease medical errors, and broaden access to essential services. AHRQ plays an important role in producing the evidence base needed to improve our nation's health and health care. 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 $364 million in base discretionary funding, consistent with the President's FY17 budget request and FY15 levels.** This investment will preserve AHRQ's current programs while helping to restore its critical health care safety, quality, and efficiency initiatives.

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

National Association of Workforce Boards

Honorable Tom Cole, Chair
Honorable Rosa DeLauro, Ranking Member
US House Appropriations Subcommittee for Labor, Health & Human Services, Education and Related Agencies
H-305 The Capitol
Washington DC 20515

Representative Cole and Representative DeLauro:

The National Association of Workforce Boards (NAWB) appreciates the opportunity to comment to the Subcommittee on Labor, Health and Human Services, Education and Related Agencies regarding the FY 2017 Federal budget. We join the Budget Committee in its view that budgets should be reflective of what a government or any organization believes is important work. When Congress historically passed the bi-partisan/bi-cameral Workforce Innovation and Opportunity Act in 2014, it transformed the workforce system and directed local business-led workforce boards to provide leadership in their local/regional workforce development systems. As the local workforce boards implement WIOA, the following objectives are top priority:

- Increase the effectiveness
- Improve the efficiency, and
- Assure access and equity in the workforce development system

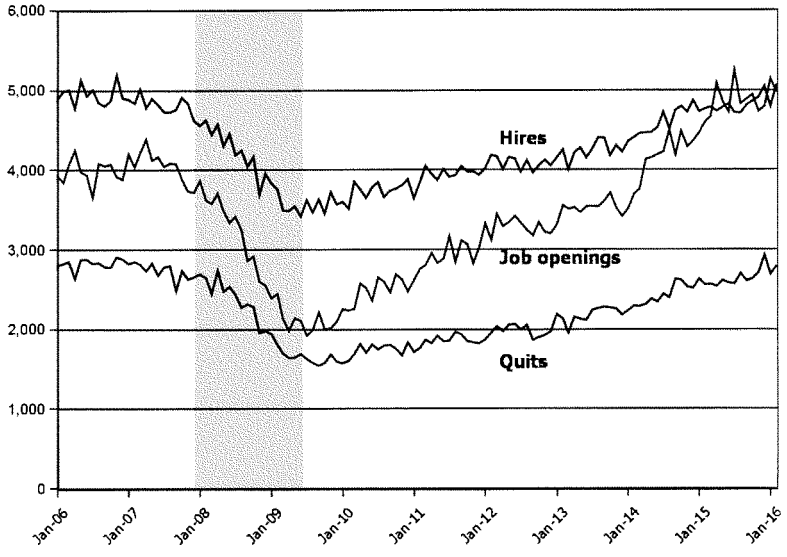
These changes will produce the return-on-investment for businesses, workers, and the federal government that should be expected.

Much has been said about the jobs recovery that has been realized since the Great Recession ended. NAWB wants to make some observations that we believe important as you consider the workforce development system. The U.S. labor market is a dynamic beast. Each month millions of individuals are hired and millions more separate from their current work confident that the market is robust enough to pursue new opportunities, or they retire or they experience a closure/laid-off and begin the process of re-skilling to re-enter the labor market.

- February hires went from 5,131,000 in 2015 to 5,422,000 in 2016, and
- February separations rose from 4,740,000 in 2015 to 5,050,000 in 2016.

The Chart below, borrowed from the Bureau of Labor Statistics's "Job Opening and Labor Turnover Survey Highlights" from February 2016, illustrates these market dynamics well.

Chart 6. Total private job openings, hires, and quits
Seasonally adjusted, in thousands



Source: Bureau of Labor Statistics, Job Openings and Labor Turnover Survey, April 5, 2016.

Note: Shaded area represents recession as determined by the National Bureau of Economic Research (NBER).

You will also note that job openings have risen as employers need to hire to meet business demands has increased. This increased demand for workers is exemplified by the workforce development system funded through the WIOA initiatives, providing services to over 19 million individuals in the period September 2014 through September 2015. A number higher than the previous annual period (2013-2014) which saw over 13 million served. Services can range from labor exchange services, someone hunting for work and finding an appropriate position listed at their local American Job Center to more intense career counseling, assessment and enrollment to up-skilling their credentials, including enrollment in entrepreneurial awareness and new/small business development.

We agree with Members of Congress who have stated that the Federal budget needs to be about the expansion of business and the attendant expansion of employment. This dynamic market requires an agile and aligned workforce development system that encompasses the PK-12 education and post-secondary education providers, specialized programming to populations with special issues and special needs, but also takes the support of transportation networks that connect people to work and housing that is affordable and near to work opportunities. In short, in a world where the talent of the labor force and the system that prepares that labor force is the

differentiation in location decisions, the Labor/HHS/Education appropriation is all about jobs and expanding the economy.

NAWB is appreciative of the efforts to restore much of the sequestered funding provided through the Bipartisan Budget Act of 2015, but the Consolidated Appropriations Act of 2016 provided "Labor-HHS" only a 3.3 percent increase over 2015 levels. Conversely, Nondefense discretionary programs were increased by 6.9 percent increase overall. As a result, funding for Americans' health, education, workforce, and social services programs—representing more than half of all nondefense discretionary spending—rose less than half as much as the nondefense average. At the same time, the Labor-HHS allocation remains about 10 percent below FY 2010 levels, adjusted for inflation.

WIOA also mandates that those with multiple barriers (long term unemployed, TANF, remedial education level) have access into the skilling needed for them to be competitive in the labor force. Many of those individuals are not ready for a job right away. The training/education needed requires a larger investment for a longer period of time. Couple that with the focus on the local boards work with industry sectors and developing career pathways rather than just taking the placement. This is not easy work and requires an enormous amount of collaboration time to build deep trusting relationships with regional community & faith-based organizations, education and industry. In short, more people, more partners, more complex work strains current resources throughout the Labor/HHS/Education appropriations.

For WIOA in particular, NAWB urges the Subcommittee to seriously consider the levels authorized in WIOA for FY 2017 of;

- Adult employment activities $842,376,000
- Dislocated Worker employment activities - $1,334,205,000
- Youth employment activities - $902,139,000
- Adult Education and Literacy - $635, 198,000

Let us offer two brief vignettes on how local workforce boards impact the labor market in their region. In Brevard County on Florida's east coast, a business needed to recertify 38 employees (manufacturing) or face losing a big contract and that would force layoffs. Compounding the need was that traditional training networks couldn't do the training for 4 months and the deadline for recertification was 3 weeks away. The community college capacity was no more than 15 at a time.

Solution – CareerSource Brevard, the County's workforce development board, heard the problem, had conversations with other manufacturers and found one willing to open their onsite training facility and teach the class. All students were taught at the same time over 2 days. CareerSource Brevard paid for 1/2 of the training costs too so it was less of an impact on the business. Total cost - under $2,000 for all 38 to be recertified! Without WIOA funds we can't jump and act on these kinds of business needs that keep people employed.

In Portland Oregon, Sary Dobhran's, life took an unexpected turn of events when she found herself suddenly widowed and pregnant with her first child. Fluent in four languages and armed with a college degree, Sary was confident she would be able to find work. After nine months of unsuccessful searching and trying to live on $400/month, while sharing a single-room with her toddler, life wasn't what she envisioned and she had to reinvent herself.

When Sary learned about the Green Careers Training Project she couldn't have been more excited. Working shoulder to shoulder with Native American Youth and Family Center and other partners, Worksystems, Portland's workforce development board, coordinated Green Careers to help people get the training and support to get ahead while also helping green businesses access a skilled workforce. Today, Sary is an assistant site auditor. She spends her days conducting energy audits for homeowners who want to save money on their utility bills and reduce their energy consumption. She loves interacting with people and above all, she loves earning a living wage with benefits that gives her and her son a better life.

We again appreciate your consideration and look forward to working with you to make the US workforce development system the envy of the world.

For the Board and membership of NAWB,

Ronald D Painter, CEO

National Association of Workforce Boards

1155 15th Street NW – Suite 350

Washington DC 20005

202.857.7900

Arthritis Foundation

Yes

Arthritis Foundation Written Testimony

House Appropriations Committee

Subcommittee on Labor, Health and Human Services, and Education and Related Agencies

Fiscal Year 2017

Contact: Sandie Preiss, National Vice President of Advocacy and Access, spress@arthritis.org, 202-887-2910

On behalf of the more than 50 million adults and 300,000 children living with doctor-diagnosed arthritis in the U.S., the Arthritis Foundation thanks Chairman Cole and Ranking Member DeLauro for the opportunity to provide written testimony to the Appropriation Subcommittee on Labor, Health and Human Services (HHS), and Education and Related Agencies for Fiscal Year 2017. **We respectfully request $16 million for the Centers for Disease Control and Prevention (CDC) Arthritis Program and sufficient funding for the National Institutes of Health (NIH) for FY 2017.**

Arthritis affects 1 in 5 Americans and is the leading cause of disability in the U.S., according to CDC. It limits the daily activities of nearly 23 million Americans and causes work limitations for 40% of the people with the disease. This translates to $156 billion a year in direct and indirect costs from two forms of arthritis alone – osteoarthritis (OA) and rheumatoid arthritis (RA). There is no cure for arthritis, and for some forms of arthritis like OA, there is no effective pharmaceutical treatment. Research is critical to

build towards a cure, to develop better treatments with fewer severe side effects, and to identify biomarkers and therapies for types of arthritis for which none exist. A strong investment in public health research and programs is essential to making breakthroughs in treatments finding a cure for arthritis, and for delivering those breakthroughs to the people who suffer from this debilitating disease.

Centers for Disease Control and Prevention (CDC) Arthritis Program

The CDC Arthritis Program is the only federal program dedicated solely to arthritis. It provides grants to 12 states to support public health programs, provide education services, perform public health research, and support data collection. Its goal is to connect all Americans with arthritis to resources to help them manage their disease. Evidence-based programs like Enhance Fitness help keep older adults active, and have shown a 35% improvement in physical function, resulting in fewer hospitalizations and lower health costs compared to non-participants. Further, 1 in 3 veterans has doctor-diagnosed arthritis, and these evidence-based exercise programs are recommended by the CDC to help our veterans reduce the impact of arthritis on their lives.

Kentucky is one of the 12 CDC-funded states, and with this federal support, the Kentucky Arthritis Program enhanced its partnership with the Kentucky Department of Aging and Independent Living to increase the delivery and sustainability of evidence-based disease management programs. The impact to-date is a 58% increase in the number of participants in the program from 2013 to 2014, translating to over 5,000 Kentuckians

having access to program services. The Kentucky program has improved the quality of life for people with arthritis by creating new social outlets, and reducing pain and medication use through the exercise and education programs.

Not only does the Arthritis Program provide resources to people with arthritis, it also supports data collection on the prevalence and severity of arthritis. Because of this support, we know that 1 in 5 Americans has doctor-diagnosed arthritis, including 27% of people in Oklahoma and 24% of people in Connecticut, and 415,000 of those people in Oklahoma and 267,000 of those people in Connecticut are limited by their arthritis. Without the Arthritis Program, the robust level of data collection we have now would not exist. As you know, this data is critical for determining where to direct public health programs and how to set research priorities. For example, because of the data on the high number of people with arthritis who also have at least one other chronic disease like heart disease (24%) or diabetes (16%), we know that research on co-morbidities and coordinated chronic disease programs are important to reducing the overall impact of chronic disease on people with arthritis.

Given the high prevalence and severity of this disease, the Arthritis Program is woefully under-funded compared to the investment in other chronic diseases. Funding for the program was cut by 25% in FY15, bringing the FY15 total down from $13 million to $9.5 million. As a result, program staff had to cut program activities between 10-50%, with some eliminations, and were unable to make new investments in arthritis programs.

While $1.5 million was restored in FY16, the Arthritis Program is still not operating at its full funding level of $13 million, and combined with previous flat funding, has lost millions of dollars in purchasing power over the last 6 fiscal years.

In 2013 for the first time, data showed that arthritis affects at least 20% of the population in every state. **All 50 states need funding from the Arthritis Program.** While this is a long-term goal, a critical first step is to increase funding in FY17 by $5 million so it can continue its current level of operations in the 12 states it supports and begin to expand into additional states. With this increase, the Arthritis Program could operate in an additional 2 states, support more national grants and increase its investment in public health research. **Therefore, we urge you to fund the CDC Arthritis Program at $16 million in FY17.**

National Institutes of Health (NIH)

As previously stated, there is no cure for arthritis, and for some forms of the disease, no effective pharmaceutical treatments. Even for auto-immune forms of the disease like RA, biologic medications – which have revolutionized treatment by halting the progress of disease in many patients – have severe side effects. There is also no "gold standard" diagnostic for many forms of arthritis like RA and juvenile arthritis, and therefore it can take a long time to diagnose these diseases. It is not uncommon for children to go months without an official diagnosis, which can delay the start of critical treatment. Research is the key to identifying better diagnostics and better treatments, so that people have access

to treatments early in their disease, ensuring a higher quality of life and better health outcomes.

The National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) is one of the primary NIH Institutes that supports arthritis research. There are a number of initiatives supported by NIAMS to better understand arthritis. The Osteoarthritis Initiative is a public-private, multi-center, longitudinal study of knee OA that was launched in 2002 with the goal of identifying biomarkers for OA as potential surrogate endpoints for onset and progression. The recently launched Accelerating Medicines Partnership is a public-private partnership that includes RA/lupus as one of three disease topics with the goal of accelerating drug development.

Research currently supported by NIAMS is addressing major questions necessary to unlocking the unknowns of arthritis, such as: how gene-environment interactions can help determine the relationship between RA and environmental and genetic factors that trigger onset; which biological pathways are affected in people with RA and how drug development can target those pathways to expand the pool of drugs available to people with RA; and how existing successful anti-rheumatic drugs may be used for other arthritis-related diseases.

Most recently, researchers have found the gene that confirms the existence of psoriatic arthritis. This is a breakthrough that has the potential to lead to targeted therapies for

psoriatic arthritis, and even treatments that can prevent its onset. These research breakthroughs can have an enormous impact on the quality of life for people with arthritis, in addition to generating a strong return on investment in reduced health care costs and better quality of life for patients.

Future research efforts can explore how changes to DNA regions can lead to disease, with the goal of uncovering additional targeted treatments. A strong overall NIH funding level is critical to maintaining the investment in research on arthritis in all its forms. **Therefore, we urge you to provide sufficient funding for NIH in FY17 to keep pace with the growing research needs in the arthritis community.**

We thank the Subcommittee for its commitment to public health. As you write the FY17 Labor-HHS-Education appropriations bill, **we urge you to fund the CDC Arthritis Program at $16 million and provide sufficient funds to the NIH in order to continue the investment in improving the lives of people with arthritis.** Please contact Sandie Preiss, the Arthritis Foundation National VP of Advocacy and Access at 202 887 2910, spreiss@arthritis.org or the Arthritis Foundation Senior Director of Advocacy and Access Anna Hyde at ahyde@arthritis.org or 202-887-2917 with any questions.

National Indian
Health Board

TESTIMONY OF THE NATIONAL INDIAN HEALTH BOARD
LESTER SECATERO, CHAIRMAN
HOUSE APPROPRIATIONS COMMITTEE - SUBCOMMITTEE ON LABOR, HHS, EDUCATION AND RELATED AGENCIES
FY 2017 WRITTEN TESTIMONY FOR THE RECORD

Chairman Cole, Ranking Member DeLauro and Members of the Subcommittee, thank you for the opportunity to offer this testimony for the record. On behalf of the National Indian Health Board (NIHB) and the 567 federally recognized Tribes we serve, I submit this testimony on FY 2017 budget for the Department of Health and Human Services (HHS).

The federal promise to provide Indian health services was made long ago. Since the earliest days of the Republic, all branches of the federal government have acknowledged the nation's obligations to the Tribes and the special trust relationship between the United States and Tribes. The United States assumed this responsibility through a series of treaties with Tribes, exchanging compensation and benefits for Tribal land and peace.[1] In 2010, as part of the Indian Health Care Improvement Act, Congress reaffirmed the duty of the federal government to American Indians and Alaska Natives (AI/ANs), declaring that "it is the policy of this Nation, in fulfillment of its special trust responsibilities and legal obligations to Indians – to ensure the highest possible health status for Indians and urban Indians and to provide all resources necessary to effect that policy." [2]

Yet, devastating consequences from historical trauma, poverty, and a lack of adequate treatment resources continue to plague Tribal communities. AI/ANs have a life expectancy 4.2 years less than other Americans, but in some areas, the life expectancy is far worse. For instance, in Montana, "white men ...lived 19 years longer than American Indian men, and white women lived 20 years longer than American Indian women."[3] In South Dakota, in 2014, "for white residents the median age [at death] was 81, compared to 58 for American Indians."[4] AI/ANs also suffer significantly higher mortality rates from suicide, type 2 diabetes, and heart disease than other Americans. According to CDC data, 45.9 percent of Native women experience intimate partner violence, the highest rate of any ethnic group in the United States. AI/AN children have an average of six decayed teeth, when other US children have only one. These health statistics reflect the shocking disparity that exists in per capita spending of the Indian Health Service (IHS) and other federal health care programs. In 2015, the IHS per capita expenditures for patient health services were just $3,136, compared to $8,097 per person for health care spending nationally.

The obligation to provide healthcare to AI/ANs does not extend only to the IHS. The federal trust responsibility is the responsibility of all government agencies, including others within HHS. Agencies like the Centers for Disease Control and Prevention (CDC); Substance Abuse and Mental Health Services Administration (SAMHSA); and Centers for Medicare and Medicaid Services (CMS) all must play a crucial role in ensuring that Indian Country receives both preventative and

[1] The Snyder Act of 1921 (25 U.S.C. 13) legislatively affirmed this trust responsibility.
[2] 25 U.S.C. 1602
[3] "The State of the State's Health: A Report on the Health of Montanans." Montana Department of Public Health and Human Services. 2013. p. 11.
[4] "2014 South Dakota Vital Statistics Report: A State and County Comparison of Leading Health Indicators." South Dakota Department of Health. 2014. P. 62.

direct access to health services. Tribal health systems are simply left out of many funding streams within HHS for a variety of reasons. Federal block grants flow to states, leaving little opportunity for Tribal governments to receive this funding. Tribes may be eligible to apply for federal grants that address public health and other issues, however, many of these programs have little penetration into Indian Country because Tribes have difficulty meeting the service population requirements, match requirements, or are under resourced to even competitively apply for the grants. Unlike state health departments which employ teams of people to write grant applications, few Tribes have enough staff to conduct basic programming, let alone work on competitive grant applications.

NIHB respectfully requests that the committee consider providing additional direct funding to Tribal communities through the use of "set asides" for Indian Country to ensure that Indian Country is not left out of federal funding opportunities. Without direct funding, Tribes are unable to develop sustainable infrastructure for public health and behavioral health programs, leading to an inconsistent and unreliable service delivery system. The federal trust responsibility requires consistent and effective investment in Tribal communities, and it is the only way that we will begin to tackle the health disparities felt by so many AI/ANs.

Centers for Disease Control and Prevention

Public Health Services Block Grant: Public health infrastructure in Indian Country is one of the most severely underfunded and under developed areas of the health service delivery system. IHS services are largely limited to direct patient care, leaving little, if any, funding available for public health initiatives such as disease prevention, health education, research for disease, injury prevention, and promotion of healthy lifestyles. This means that Indian Country continues to lag far behind other communities in basic resources and services. Our communities are therefore more vulnerable to increased health risks and sickness.

As independent, sovereign nations, Tribal governments do not operate within the state regulatory structure, and often must compete with their own state governments for resources. Tribes are regularly left out of statewide public health plans and federal funding decisions for public health programs. Without a local tax base and little (if any) outside funding, Tribal communities are often the most in need of public health dollars. A complex public health system exists in the US that includes a funding stream between the federal and state governments that largely support the national public health infrastructure – Tribes were excluded from this system. Tribes do not receive the federal funding that allows state health departments to function. It is time to examine how Tribes can be integrated into the US public health system, and redress this wrong.

Tribal communities must cobble together public health funding from a variety of federal, state, local and private funding sources. State governments receive base operational systems and programmatic funding through the large flagship federal grants and the Public Health and Health Services Block (PHHS) grant program, while Tribes are either not eligible to compete for the funding or are woefully underrepresented in the grantee pool. This leads to rampant unpredictability and inconsistency among Tribal public health initiatives, and leaves Indian Country with little public health infrastructure. Consequently, significant gaps exist when it comes to health education, emergency preparedness, community healthcare services and basic healthcare screenings. Therefore, NIHB requests that, in FY 2017, ***Congress create base funding for Tribal***

communities through the PHHS grant program by allocating at least 5 percent to Indian Tribes directly, annually. This will enable public health systems in Indian Country to access consistent, sustainable, public health infrastructure dollars so that Tribal communities can begin to catch up to other Americans when it comes to public health.

Hepatitis C Treatment in Indian Country: According to the CDC's most recent surveillance report on hepatitis C, in 2013, AI/ANs were the population with the highest hepatitis C-related mortality rate at 12.2 deaths per 100,000 people. This is 46% higher than the next highest population death rate. And between 2009 and 2013, the hepatitis C-related mortality rate among American Indians and Alaska Natives increased by 23.2%. The hepatitis C (HCV) scourge among AI/AN communities continues to grow out of control with no substantial dedication of resources or commitment by HHS to provide for targeted prevention, capacity building, and treatment. Treatment, that very nearly mirrors a cure, is readily available; however, community members may not be sure how to access the treatments, and Tribes have competing priorities and are reticent to utilize scarce IHS resources to secure the treatment. Even more so, prevention efforts to promote HCV screening have not been bolstered in Tribal communities, service providers have not been trained to talk to their patients about hepatitis risks and testing options, nor have efforts existed to educate the community and high risk populations about their ability to minimize their risks for exposure to HCV.

Therefore, NIHB recommends that ***Congress direct the CDC to create a grant program specifically for AI/ANs that will provide monies for community-based prevention and screening efforts for HCV.*** Furthermore, we request that CDC be instructed to work with IHS to ***construct a targeted action plan for promoting the prevention of hepatitis C***, increasing screening efforts and increasing access to treatment.

Public Health Emergency Preparedness: The Public Health Emergency Preparedness (PHEP) Cooperative Agreements at CDC provide base funding to states, territories and major cities to upgrade their ability to respond to a public health crises. But again, Tribal communities do not receive this funding directly, and few, if any, see any support from their state programs. Some Tribal reservations reach across state boundaries and others occupy land areas larger than many states. Without federally-supported infrastructure support for prevention and rapid response to natural disasters, bioterrorism and outbreaks in Indian Country, the impacts on American Indians and Alaska Natives (and others) could be enormous. And with the looming threat of the Zika Virus, this is even more urgent – as a significant percentage of Tribes occupy those lands projected to be in danger due to the habitat of the mosquito that transmits the virus. Failure to fund Tribal communities and reservations could mean that large land areas of this country are not covered for emergency infrastructure support, causing a domino effect throughout the rest of the nation when it comes to disease outbreaks or natural disasters. NIHB requests that ***Congress direct 5% of PHEP funds to Tribes so that they can develop serious and achievable response plans for public health crises.***

Substance Abuse and Mental Health Services Administration

Nowhere is the issue of lack of solid infrastructure support more acute than mental and behavioral health services. AI/AN children and communities grapple with complex behavioral health issues at higher rates than any other population. Destructive federal Indian policies and unresponsive or

harmful human service systems have left AI/AN communities with unresolved historical and generational trauma.[5] Where Tribal reclamation of these systems has been possible, it has led to effective service systems designed and implemented, by and for AI/AN people, to promote cultural strength and healing. These Tribal systems have already begun to resolve the trauma left behind by federal policies and systems. But access to behavioral health services is limited. In a study of 514 IHS and Tribal facilities, 82% report providing some type of mental health service such as psychiatric services, behavioral health services, substance abuse treatment, or traditional healing practices, and to improve access 17% (87) have implemented telemedicine for mental health services.[6] However, none provide inpatient psychiatric services.[7] Without access to care, persons in psychiatric distress often end up at the hospital emergency room.[8]

Tribal Behavioral Health Grants and Zero Suicide: At the Substance Abuse and Mental Health Services Administration, several programs specifically target Tribal communities. NIHB was pleased to see that Tribal Behavioral Health Grants (TBHG) received a substantive increase in the final FY 2016 appropriation. This critical program is designed to address the high incidence of substance use and suicide among AI/AN populations and it is a vital component of ensuring that behavioral health challenges are addressed across Indian Country. In FY 2017, NIHB requests ***funding of $50 million for the TBHG program.*** We also request that ***funds to be appropriated for specific, predetermined issues:*** namely, suicide interventions, expansion of mental health counseling capacity and infrastructure, and surveillance of and mediation for increasing levels of domestic violence. NIHB also ***supports the Administration's FY 2017 request for $5.2 million in a Tribal set-aside to implement the Zero Suicide Initiative.***

Circles of Care: NIHB continues to support the Circles of Care Program which offers three-year infrastructure/planning grants and seeks to eliminate mental health disparities by providing AI/AN communities with tools and resources to design and sustain their own culturally competent system of care approach for children. Behavioral health infrastructure is one of the key challenges for many Tribal communities when it comes to creating sustainable change for their communities. Circles of Care represents a critical part of this work. ***In FY 2017, we recommend increasing Circles of Care funding by $2 million for a program total of $8.5 million.***

NIHB also encourages Congress to conduct oversight over SAMHSA, IHS and other federal agencies to ensure that the work being done to address behavioral health issues in Tribal communities is coordinated, effective, and non-duplicative, as laid out in the Tribal Behavioral Health Agenda being released by SAMHSA this coming summer.

Centers for Medicare and Medicaid Services

Definition of Indian in the Affordable Care Act: The Affordable Care Act (ACA) (PL 111-148) contains several important provisions for American Indians and Alaska Natives including

[5] Braveheart, M. Y. A., & DeBruyn, L. M. (1998). The American Indian Holocaust: healing historical unresolved grief. *American Indian and Alaska Native Mental Health Research, 8*(2).

[6] Urban Indian Health Institute. (2012). Addressing depression among American Indians and Alaska Natives: A literature review. Seattle, WA: Urban Indian Health Institute.

[7] Indian Health Service. (2011). *Inpatient mental health assessment.* Retrieved from http://www.ihs.gov/newsroom/includes/themes/newihstheme/display_objects/documents/FINAL_IHCIA_InpatientMH_Assessment_Final.pdf

[8] *Ibid*

permanent reauthorization of the Indian Health Care Improvement Act. However, certain portions of health care reform contain different definitions of "Indian" which led to conflicting interpretations of eligibility for benefits and requirements for coverage. These definitions are different than those used by IHS and the Centers for Medicare and Medicaid Services and require that an individual be a member of a federally recognized Tribe.

NIHB requests a legislative fix to streamline these definitions. Specifically, we request that Congress ***insert the text of S. 2114 into the FY 2017 Labor, HHS, Education and Related Agencies Appropriations bill.*** Despite efforts by Congress to provide instructions to the agency in FY 2016, the Administration has refused to correct this inconsistency through regulation. This fix will not change who is eligible to receive IHS services, but will ensure that the benefits and protections in the law are provided to those for whom they were intended. Without a fix, many AI/ANs will be left out of benefits intended for them in the law, which includes bringing 3rd party revenue into an already underfunded IHS. Without a fix, the federal government will essentially create class of "sometimes Indians" who are eligible for some benefits (e.g. IHS) but not others (those in the ACA). This fix is supported in the FY 2017 President's Budget request to Congress.

American Indian/ Alaska Native Call Center for the Health Insurance Marketplace: AI/ANs continue to experience poor assistance when contacting the marketplace call center for help. Issues range from technicians having no knowledge of the Indian-specific protections like exemptions and tax credits, to technicians being rude and having no patience to walk elderly consumers through the troubleshooting process. Because AI/AN consumers continue to receive such poor customer service that exhibit little or no knowledge about AI/AN-specific provisions in the ACA, NIHB has requested that the Center for Consumer Information and Insurance Oversight (CCIIO) establish an Indian-specific call center to respond to questions and provide technical assistance to AI/ANs, as well as non-native enrollment assisters such as Navigators and Certified Application Counselors. We also believe that an Indian-specific help desk would be better equipped and more sensitive to the needs of AI/AN consumers.

The Administration's proposed FY 2017 budget provides for the creation of a "Tribal Resource Center," or other Tribal specific project, where staff would be trained and skilled in responding to inquiries from the Tribal community relating to enrollment into the full range of CMS health insurance programs. NIHB recommends that Congress ***provide funding for the Tribal Resource Center at the Center for Medicare and Medicaid Services at $500,000 as requested by CMS.***

Conclusion:

Thank you again for the opportunity to offer this written statement. As noted above, the federal trust responsibility for health extends beyond the IHS to all agencies of the federal government. While Tribes have made important gains in recent years in terms of funding, consultation and increased awareness throughout all of HHS, there is still a long way to go before health systems in Indian Country are on par with those enjoyed by other Americans.

We urge this Committee to create Tribal-specific streams of funding for these "flagship" grant programs that go to the state governments, so that Indian Country can access federal funds that are desperately needed to build a strong, consistent, health delivery system. Please do not hesitate to contact our offices directly if you have any questions or if you require additional information.

Testimony from Amber Williams, Executive Director, Safe Sates Alliance Concerning the Centers for Disease Control and Prevention's FY2017 Appropriations

Submitted for the Record to the House Appropriations Subcommittee on Labor, Health and Human Services, Education, and Related Agencies – April 15, 2016

Safe States Alliance, the national membership association dedicated to strengthening the practice of injury and violence prevention, appreciates the opportunity to provide testimony in support of injury and violence prevention programs at the Centers for Disease Control and Prevention (CDC) and Health Resources and Services Administration (HRSA). Safe States Alliance requests that as you craft the FY2017 Labor, Health and Human Services and Education Appropriations bill, you consider including the following priorities:

- $20M to expand the *State Core Violence and Injury Prevention Program*;
- $5M to pursue a traumatic brain injury (TBI) surveillance program;
- $25M for nationwide expansion of the *National Violent Death Reporting System*;
- Preserve the *Prevention and Public Health Fund* and allocate resources to support injury and violence prevention efforts;
- Maintain funding for the *Preventive Health and Health Services Block Grant* at $180M and provide $650M to HRSA for the *Maternal and Child Health Block Grant*;
- $19M to increase youth violence prevention-related investments across all federal agencies, including restoration of funding for *youth violence prevention* activities;
- $10M to research the causes and prevention of firearm-related violence and injuries; and,
- $18M for the *Injury Control Research Centers* for interdisciplinary research and train future injury and violence prevention practitioners and researchers.

BACKGROUND

In 1985, the Institute of Medicine (IOM) first called attention to the lack of recognition and funding for injury and violence prevention (IVP) as a public health issue in the United States.[1] Although some progress has been made, injuries and violence continue to have a significant impact on the health of Americans and the healthcare system, as more people ages 1–44 die from injuries than from any other cause, including cancer, HIV, or the flu.[2]

Injuries and violence are serious public health problems. Areas include:	
Assault & Homicide	Motor Vehicle Safety
Bullying	Pedestrian & Bicycle Safety
Child Maltreatment	Poisoning & Prescription Drug Overdose
Child Passenger Safety	Sexual Assault & Rape
Disaster Response	Suicide
Domestic & Intimate Partner Violence	Traumatic Brain Injury
Drowning	Youth Violence
Elder Abuse	
Falls	
Fire & Burns	

In fact, in 2013 injury and violence resulted in more than 27 million visits to emergency departments, three million hospitalizations, and roughly 193,000 deaths—one person every three minutes.[2] Furthermore, in 2013 injuries and violence cost $671 billion in medical costs and lost productivity.[3] Yet, today there is no national program to support state public health IVP programs.

At the federal level, the CDC Injury Center serves as the focal point for the public health approach to IVP. The CDC Injury Center only receives approximately three percent of the CDC/ Agency for Toxic Substances and Disease Registry budget to address the significant burden of injuries and violence nationwide.

CORE VIOLENCE AND INJURY PREVENTION PROGRAM (VIPP)

Given its limited budget, the CDC Injury Center currently provides small capacity building grants of approximately $250,000 to only 20 state health departments (SHDs) through the Core Violence and Injury Prevention Program (VIPP). The Core VIPP is comprised of multiple components including: Basic Prevention (20 states); Regional Network Leaders (five states);

Surveillance Quality Improvement (four states); Older Adult Falls Prevention (three states); and Motor Vehicle/Child Injury Prevention (four states).

Opioid pain relievers are now involved in more overdose deaths than cocaine and heroin combined. From 2000 to 2014 nearly half a million people died from drug overdoses. The CDC Injury Center provides leadership in enhancing drug overdose surveillance, identifying and evaluating effective program and policy interventions for preventing overdoses, improving clinical practice to reduce prescription drug diversion and abuse, and equipping and empowering states with the information and resources they need to reverse the epidemic. Due to limited funding, a small number of Core VIPP states support promising surveillance and prevention strategies. State health departments are well positioned to coordinate the necessary multi-sector responses to reverse the epidemic through the regulation of health care professionals, prescription drug monitoring programs, and other major levers for preventing prescription drug abuse.

Ohio's Core Violence and Injury Prevention Program (VIPP) provides statewide leadership and funding for community-based efforts to address prescription drug abuse and overdose through the PHHS Block Grant from CDC. The OH VIPP coordinates the development and implementation of statewide prevention strategies, conducts surveillance, supports the Governor's Cabinet Opiate Action Team Prescriber Education Work Group including the development of opioid prescribing guidelines, and provides support and technical assistance to expand naloxone distribution programs. Examples of locally PHHS Block Grant funded strategies include: expanding access to naloxone distribution programs; facilitating health care system changes such as implementation of opioid prescribing guidelines and other pain

management strategies; obtaining commitment of prescribers to use the Ohio prescription drug monitoring program; and expanding access to sustainable drug disposal options.

Safe States Alliance recommends an allotment of $20M for the Core VIPP to support injury and violence prevention programs in ALL states and territories and full funding for the Preventive Health and Health Services Block Grant at $180M.

NATIONAL VIOLENT DEATH REPORTING SYSTEM (NVDRS)

NVDRS is a state-based surveillance system that uses information from a variety of states and local agencies and sources – medical examiners, coroners, police, crime labs and death certificates – to form a more complete picture of the circumstances that surround violent deaths. State and local violence prevention practitioners use these data to guide their prevention programs, policies and practices including: identifying common circumstances associated with violent deaths of a specific type (e.g. gang violence) or a specific area (e.g. a cluster of suicides); assisting groups in selecting and targeting violence prevention efforts; supporting evaluations of violence prevention activities; and improving the public's access to in-depth information on violent deaths. CDC Injury Center currently funds 32 states to implement NVDRS and received an approximately $5M increase in FY 2016 to expand number of participating states.

In Oregon, the Oregon Older Adult Suicide Prevention Advisory Work Group and the Oregon Department of Human Services used NVDRS to develop and focus suicide prevention programs for older adults. NVDRS found that almost 50% of men ages 65 and older who died by suicide were reported to have a depressed mood before death, but only a small proportion were receiving treatment, suggesting screening and treatment for depression might have saved lives. As a result, Oregon developed primary care recommendations in 2006 to better integrate with mental health services so that suicidal behavior and ideation are diagnosed and older adults

received appropriate treatment. As a result, the suicide rates among males ages 65 and older in Oregon decreased approximately eight percent from 2007 to 2010.

Safe States Alliance supports an increase of $7.5M to complete nationwide expansion of NVDRS.

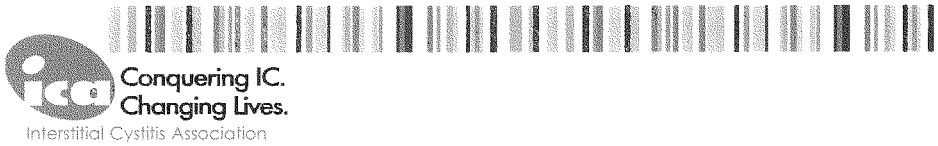
PREVENTIVE HEALTH AND HEALTH SERVICES (PHHS) BLOCK GRANT

For more than 30 years, the PHHS Block Grant has remained an essential source of federal agencies to support state solutions to state health problems. The PHHS Block Grant allows each state to respond to its own distinct health priorities and need and is the only source of funding for states without Core VIPP that supports local IVP prevention efforts. In FY 2011, more than 20 percent of the Prevent Block Grant was used by states to support IVP and emergency medical services. According to a 2011 survey conducted by Safe States Alliance, 29 states reported receiving an average of $329,000 from the Prevent Block Grant for IVP efforts.[4] The Prevent Block Grant is a critical source of funding for SHD IVP programs representing 9.4 percent of total state funding in 2011. *Safe States Alliance supports continued funding of the PHHS Block Grant at the $180 million level.*

Preventable injuries exact a heavy burden on Americans through premature deaths and disabilities, pain and suffering, medical and rehabilitation costs, disruption of quality of life for families, and disruption of productivity for employers. Strengthening investments in public health IVP programs is a critical step to keep Americans safe and productive for the 21st century. Safe States Alliance would like to thank the Committee for consideration of this testimony.

---

[1] National Research Council. Injury in America: A Continuing Public Health Problem. Washington, DC: The National Academies Press, 1985.
[2] Centers for Disease Control and Prevention, National Center for Injury Prevention and Control. Web-based Injury Statistics Query and Reporting System (WISQARS) [online] (2007) [accessed 2013 Feb 15]. Available from URL: http://www.cdc.gov/injury/wisqars.
[3] Centers for Disease Control and Prevention, National Center for Injury Prevention and Control. Web-based Injury Statistics Query and Reporting System (WISQARS) [online] (2007) [accessed 2013 Feb 15]. Available from URL: http://www.cdc.gov/injury/wisqars
[4] State of the States: 2011 Report. Atlanta, GA: Safe States Alliance; 2013.



STATEMENT OF LEE CLAASSEN
EXECUTIVE DIRECTOR
INTERSTITIAL CYSTITIS ASSOCIATION

REGARDING FISCAL YEAR 2017 APPROPRIATIONS
FOR THE CENTERS FOR DISEASE CONTROL AND PREVENTION
AND NATIONAL INSTITUTES OF HEALTH

SUBMITTED TO THE HOUSE COMMITTEE ON APPROPRIATIONS
SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES,
EDUCATION, AND RELATED AGENCIES

APRIL 15, 2016

SUMMARY OF RECOMMENDATIONS FOR FISCAL YEAR 2017:

- **PROVIDE $1 MILLION FOR THE IC EDUCATION AND AWARENESS PROGRAM AND THE IC EPIDEMIOLOGY STUDY AT THE CENTERS FOR DISEASE CONTROL AND PREVENTION (CDC)**
- **PROVIDE $7.8 BILLION FOR CDC**
- **PROVIDE $34.5 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**

Thank you for the opportunity to present the views of the Interstitial Cystitis Association (ICA) regarding interstitial cystitis (IC) public awareness and research. ICA was founded in 1984 and is the only nonprofit organization dedicated to improving the lives of those affected by IC. The Association provides an important avenue for advocacy, research, and education. Since its founding, ICA has acted as a voice for those living with IC, enabling support groups and empowering patients. ICA advocates for the expansion of the IC knowledge-base and the development of new treatments. ICA also works to educate patients, healthcare providers, and the public at large about IC.

IC is a condition that consists of recurring pelvic pain, pressure, or discomfort in the bladder and pelvic region. It is often associated with urinary frequency and urgency. This condition may also be referred to as painful bladder syndrome (PBS), bladder pain syndrome (BPS), and chronic pelvic pain (CPP). It is estimated that as many as 12 million Americans have IC symptoms. Approximately two-thirds of these patients are women, though this condition does severely impact the lives of as many as 4 million men. IC has been seen in children and many adults with IC report having experienced urinary problems during childhood. However, little is known about IC in children, and information on statistics, diagnostic tools and treatments specific to children with IC is limited.

The exact cause of IC is unknown and there are few treatment options available. There is no diagnostic test for IC and diagnosis is made only after excluding other urinary/bladder conditions. It is not uncommon for patients to experience one or more years delay between the onset of symptoms and a diagnosis of IC. This is exacerbated when healthcare providers are not properly educated about IC.

The effects of IC are pervasive and insidious, damaging work life, psychological well-being, personal relationships, and general health. The impact of IC on quality of life is equally as severe as rheumatoid arthritis and end-stage renal disease. Health-related quality of life in women with IC is worse than in women with endometriosis, vulvodynia, and overactive bladder. IC patients have significantly more sleep dysfunction, and higher rates of depression, anxiety, and sexual dysfunction.

Some studies suggest that certain conditions occur more commonly in people with IC than in the general population. These conditions include allergies, irritable bowel syndrome, endometriosis, vulvodynia, fibromyalgia, and migraine headaches. Chronic fatigue syndrome, pelvic floor dysfunction, and Sjogren's syndrome have also been reported.

IC PUBLIC AWARENESS AND EDUCATION THROUGH CDC

ICA recommends a specific appropriation of $1 million in fiscal year 2017 (FY17) for the CDC IC Program. This will allow CDC to fund the Education and Awareness Program, per ongoing congressional intent, as well as the IC Epidemiology Study.

In December 2014, CDC switched the focus of the IC program from education and awareness to an epidemiology study. The IC community is concerned that eliminating education and awareness activities is detrimental to patients and their families. The CDC IC Education and Awareness Program is the only federal program dedicated to improving public and provider awareness of this devastating disease, reducing the time to diagnosis for patients, and disseminating information on pain management and IC treatment options. ICA urges Congress to provide funding for IC education and awareness in FY17.

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 $34.5 billion for NIH in FY17. ICA also recommends continued support for IC research including the MAPP Study administered by NIDDK.

The National Institutes of Health (NIH) maintains a robust research portfolio on IC with the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) serving as the primary Institute for IC research. Research currently underway holds great promise to improving our understanding of IC and developing better treatments and a cure. The NIDDK Multidisciplinary Approach to the Study of Chronic Pelvic Pain (MAPP) Research Network studies the underlying causes of chronic urological pain syndromes, including epidemiology. The MAPP Study has expanded in its second phase to include cross-cutting researchers and researchers are currently identifying different phenotypes of the disease. Phenotype information will allow physicians to prescribe treatments with more specificity. Research on chronic pain that is significant to the community is also supported by the National Institute of Neurological Disorders and Stroke (NINDS) as well as the National Center for Complementary and Integrative Health (NCCIH). Additionally, the NIH investigator-initiated research portfolio continues to be an important mechanism for IC researchers to create new avenues for interdisciplinary research.

Thank you for the opportunity to present the views of the interstitial cystitis community.

AMERICAN GERIATRICS SOCIETY
Written Testimony for the Record – Fiscal Year 2017 Appropriations
Subcommittee on Labor, Health and Human Services, Education, and Related Agencies
Committee on Appropriations
United States House of Representatives

April 15, 2016

Written Testimony for FY 2017 Appropriations for the Department of Health and Human Services

- **Geriatrics Education and Training Programs**
- **Additional workforce programs in the Health Resources and Services Administration**
- **National Institutes of Health/National Institute on Aging**

Submitted on behalf of the American Geriatrics Society
40 Fulton Street, 18th Floor
New York, NY 10038
Contact: Anna Mikhailovich, Senior Coordinator of Public Affairs and Advocacy,
amikhailovich@americangeriatrics.org

Mr. Chairman and Members of the Subcommittee,

We submit this testimony on behalf of the American Geriatrics Society (AGS), 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 (FY) 2017 Labor-HHS Appropriations Bill, we ask that you prioritize funding for the geriatrics education and training programs under Title VII and Title VIII of the Public Health Service (PHS) Act, additional primary care programs under the Health Resources and Services Administration (HRSA), and for aging research within the National Institutes of Health (NIH)/National Institute on Aging (NIA).

We ask that the subcommittee consider the following funding levels for these programs in FY 2017:

- **$45 million for the Geriatrics Workforce Enhancement Program** *(PHS Act Title VII, Sections 750 and 753(a) and PHS Act Title VIII, Section 865)*
- **$9.7 million for additional primary care workforce programs under HRSA**
- **An increase of $500 million over the FY 2016 enacted level for aging research across the NIH, in addition to the funding allocated for Alzheimer's disease and related dementias**

Sustained and enhanced federal investments in these initiatives are essential to delivering high quality, better coordinated, and more cost effective care to our nation's seniors, whose numbers are projected to increase dramatically in the coming years. According to the U.S. Census Bureau, the number of people age 65 and older will more than double between 2010 and 2050 to 88.5 million or 20 percent of the population; and those 85 and older will increase threefold to 19 million. To ensure that our nation is prepared to meet the unique healthcare needs of this rapidly growing population, we request that Congress provide additional investments necessary to expand and enhance the geriatrics workforce, which is an integral component of the primary care workforce, and to foster groundbreaking medical research.

PROGRAMS TO TRAIN GERIATRICS HEALTHCARE PROFESSIONALS

Our nation is facing a critical shortage of geriatrics faculty and healthcare professionals across disciplines. This trend must be reversed if we are to provide our seniors with the quality care they need and deserve. Care provided by geriatrics healthcare professionals, who are trained to care for the most complex and frail individuals who account for 80 percent of our Medicare expenditures, has been shown to reduce common and costly conditions that are often preventable with appropriate care, such as falls, polypharmacy, and delirium.

Geriatrics Workforce Enhancement Program ($45 million)

The Geriatrics Workforce Enhancement Program (GWEP) is currently the only federal program designed to increase the number of providers, in a variety of disciplines, with the skills and training to care for older adults.

In May 2015, HRSA announced 41 three-year grant funded programs that consolidated the Title VIII Comprehensive Geriatric Education Program and the Title VII Geriatric Academic Career Award, Geriatric Education Centers, and Geriatric Training for Physicians, Dentists and Behavioral and Mental Health Providers programs.

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

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

To address this issue, we request additional funding for the Title VII and Title VIII geriatrics professions programs for FY 2017:

- **Geriatrics Workforce Enhancement Program ($45 million)**

  GWEP seeks to improve high-quality, interprofessional geriatric education and training to the health professions workforce, including geriatrics specialists, as well as increase geriatrics competencies of primary care providers and other health professionals to improve care in medically underserved areas. It supports the development of a healthcare workforce that improves health outcomes for older adults by integrating geriatrics with primary care, maximizing patient and family engagement and transforming the healthcare system. We ask the subcommittee to provide a FY 2017 appropriation of $45 million for the Geriatrics Workforce Enhancement Program. With more resources available, we also ask for a renewed emphasis to address the severe shortfall of faculty with expertise in geriatrics and gerontology.

Additional Workforce Programs under the Health Resources and Services Administration ($9.7 million)

- **National Health Care Workforce Commission ($3 million)**

  The National Health Care Workforce Commission was established in the Affordable Care Act to identify barriers to healthcare workforce development and to formulate a national strategy to address the shortage; however, Congress has not provided funding for the Commission to be convened. The AGS believes that the Commission's work—including research on topics such as workforce priorities and goals; current and projected workforce supply; and needs and assessments of current education and training activities—is an important first-step in the effort to bolster the healthcare workforce in order to meet the needs of the burgeoning number of older Americans. We request $3 million for the Commission so that it can accomplish its essential mission.

- **Geriatric Career Incentive Awards Program ($3.3 million)**

  Congress authorized this program under the Affordable Care Act to provide financial support to foster greater interest among a variety of health professionals entering the field of geriatrics, long-term care, and chronic care management. Our funding request includes $3.3 million for this program.

- **Training Opportunities for Direct Care Workers ($3.4 million)**

  Under the Affordable Care Act, Congress approved a program that will offer advanced training opportunities for direct-care workers. The AGS believes this program should be funded to improve training and enhance the recruitment and retention of direct care workers, particularly those in long-term care settings. As our population ages, these workers are an integral part of efforts to ensure that older adults have access to high-quality care. We are requesting $3.4 million for this program.

RESEARCH FUNDING INITIATIVES

National Institutes of Health (additional $500 million over FY 2016)

The institutes that make up the NIH and specifically the NIA lead the national scientific effort to understand the nature of aging and to extend the healthy, active years of life. As a member of the Friends of the NIA, a broad-based coalition of aging, disease, research, and patient groups committed to the advancement of medical research that affects millions of older Americans—the AGS urges a minimum increase of $500 million over the enacted FY 2016 level in the FY 2017 budget for biomedical, behavioral, and social sciences aging research efforts across the NIH. The AGS also supports an additional $400 million for NIH-funded Alzheimer's disease and related dementias research over the enacted FY 2016 level.

The federal government spends a significant and increasing amount of funds on healthcare costs associated with age-related diseases. By 2050, for example, the number of people age 65 and older with Alzheimer's disease and related dementias is estimated to reach 13.8 million—nearly triple the number in 2016—and is projected to cost more than $1 trillion. Further, chronic diseases related to aging, such as diabetes, heart disease, and cancer continue to afflict 80 percent of people age 65 and older and account for more than 75 percent of Medicare and other federal health expenditures. Continued and increased federal investments in scientific research will ensure that the NIH and NIA have the resources to conduct groundbreaking research related to the aging process, foster the development of research and clinical scientists in aging, provide research resources, and communicate information about aging and advances in research on aging.

Strong support such as yours will help ensure that every older American is able to receive high-quality care.

Thank you for your consideration.

Testimony Prepared by Jacquelyn Kilmer, Esq., CEO, Harlem United, for the United States House Committee on Labor, Health and Human Services, as well as Education and Related Agencies, Addressed to the Department of Health and Human Services

April 15, 2015

Harlem United is part of the nationwide Food is Medicine Coalition of over 80 food and nutrition services providers, affiliates, and their supporters providing food and nutrition services to people living with HIV/AIDS (PLWHA) and other chronic illnesses. **In Harlem and the South Bronx in New York City, we provide nearly 12,000 medically tailored, hot and nutritious meals to over 270 unique clients per year.**

As part of the Food is Medicine Coalition, Harlem United is committed to increasing awareness of the essential role that food and nutrition services (FNS) play in successfully treating HIV/AIDS and to expanding access to this indispensable intervention for people living with other severe illnesses.

Why Food and Nutrition Services (FNS) Matter for PLWHA
While adequate food and nutrition are basic to maintaining health for all persons, good nutrition is crucial for the management of HIV infection. For example, proper nutrition is needed to increase absorption of medication, reduce side effects, and to maintain healthy body weight.

Research has also identified HIV as an independent risk factor for cardiovascular, liver and kidney disease, cancer, osteoporosis and stroke. Additionally, several HIV medications can cause nausea and vomiting, and some can also affect lab results that test lipids and kidney and liver function. These compounding health effects reinforce the important role a nutrient-rich diet plays in patients' overall care plans.

In addition, providing FNS at Harlem United facilitates connection to and engagement with the primary medical and dental care, housing, substance use treatment, and other services we provide, especially among vulnerable populations. In fact, over 50 percent of our FNS clients are actively engaged in other programs and services provided by Harlem United.

The Food and Nutrition Services category within the Ryan White Program includes medical nutritional therapy (MNT) and FNS. MNT covers nutritional diagnostic, therapy, and counseling services focused on prevention, delay or management of diseases and conditions. MNT also involves an in-depth assessment, periodic reassessment and intervention provided by a licensed, Registered Dietitian Nutritionist (RDN) outside of a primary care visit.

The range of FNS provided through the Ryan White program complements the needs of PLWHA at any stage of their illness. For those who are most mobile, there

are congregate meals, such as what we provide to clients at our two Adult Day Health Care (ADHC) programs, as well as walk-in food pantries and voucher programs. For those whose disease has progressed, home-delivered meals and home-delivered grocery bags complement their medical treatment.

Since 2006, HRSA has included MNT and FNS, provided under the guidance of RDNs, as a clinically effective, core medical service in the Ryan White Program. These services play a critical role in ensuring that PLWHA enter and continue in primary medical care, adhere to their medications, and ultimately achieve viral suppression.

FNS as a Care Completion Service Unique to Ryan White
Social and economic interventions, most often in the form of care completion service like FNS, are fundamental to making health care work for PLWHA. Support services for this population are not covered in any comprehensive way by Medicaid or other public insurance initiatives that have been expanded by the Affordable Care Act (ACA). As the HIV epidemic in the United States increasingly impacts low-income individuals, support services help stabilize individuals living with or at risk of HIV. When needs are met, and life's emergencies are held at bay, PLWHA remain connected to care and treatment.

Access to FNS and the Triple Aim
Access to FNS is increasingly recognized as key to accomplishing the triple aim of national healthcare reform for PLWHA.

1. **Better Health Outcomes**
   When clients receive effective FNS and become food secure, they are more likely to keep scheduled primary care visits, score higher on health functioning, are at lower risk for inpatient hospital stays, and are more likely to take their medications.[1] Studies show both the health benefits of access to MNT and/or nutrition counseling for people with HIV infections and the resulting decreases in their healthcare costs.[2] Compare these outcomes to PLWHA who are food insecure, who have:
   - Lower CD4 counts & lower likelihoods of having undetectable viral loads[3]
   - More ER visits[4] & increased morbidity and mortality[5]
   - More missed primary care appointments & reduced use of antiretroviral therapy[6]

2. **Lower Healthcare Costs**
   Millions of dollars in healthcare expenditures are saved through the provision of FNS to PLWHA. A recent study comparing participants in a medically-tailored FNS program to a control group within a local managed care organization found that average monthly healthcare costs for PLWHA fell 80 percent in the first three months after receiving FNS.[7] If hospitalized, nourished clients' costs were 30 percent lower, their hospital length of stay was cut by 37 percent, and they were 20 percent more likely to be able to be

discharged to their homes rather than a more expensive institution.[8] Furthermore, FNS are a very inexpensive intervention. For each day in a hospital saved, you can feed a person a medically-tailored diet for half a year.

3. **Improved Patient Satisfaction**
   Studies show nutrition counseling improves quality of life.[9] Members overwhelmingly report that our services help them live more independently, eat more nutritiously, and manage their medical treatment more effectively.

FNS and the National HIV/AIDS Strategy (NHAS)
Access to FNS for PLWHA is fundamental to fulfilling the goals of the NHAS.

1. **Reducing new HIV infections:** PLWHA who are food insecure are statistically significantly less likely to have undetectable viral loads. Undetectable viral loads prevent transmission 96 percent of the time,[10] thus FNS is key to prevention.[11]

2. **Increasing access to care and improving health outcomes for people living with HIV:** PLWHA who receive effective FNS are more likely to keep scheduled primary care visits, score higher on health functioning, are at lower risk for inpatient hospital stays, and are more likely to take their medications.[12]

3. **Reducing HIV-related disparities and health inequities:** By providing FNS to PLWHA who are in need largely because of poverty, we improve health outcomes and reduce health disparities.[13]

4. **Achieving a more coordinated national response to the HIV epidemic:** There remains a tremendous variation by state in coverage of FNS, both inside and outside of Ryan White, making support for Ryan White HIV Programs all the more needed. Ultimately, if we are going to achieve a more coordinated, national response to the HIV epidemic, as well as our quest to reduce healthcare spending nationwide, FNS must be included in all healthcare reform efforts, including Ryan White and the ACA.

Conclusion
We are deeply aware of the difficult decisions that face the members of the Committee in the current fiscal environment. Yet, research shows that investment in FNS, with the great return in prevention and retention in HIV care, is vital to lowering the number of new infections in the domestic HIV epidemic, and to ultimately reducing healthcare costs and preserving healthcare resources for the future.

A client's diet has life and death consequences. When people are severely ill, good nutrition is one of the first things to deteriorate, making recovery and stabilization that much harder, if not impossible. Early and reliable access to medically-

appropriate FNS helps PWH live healthy and productive lives, produces better overall health outcomes, and reduces health care costs.

Along with our Food is Medicine Coalition colleagues, we appreciate the opportunity to offer this testimony regarding the FY 2017 Appropriations process.

Thank you.

Jacquelyn Kilmer, Esq.
CEO
Harlem United
306 Lenox Avenue, FL 3
New York, NY 10027

[1] Aidala A, Yomogida M, Vardy Y & the Food & Nutrition Study Team. Food and Nutrition Services, HIV Medical Care, and Health Outcomes. New York State Department of Health: Resources for Ending the Epidemic, 2014. Available at https://www.health.ny.gov/diseases/aids/ending_the_epidemic/docs/key_resources/housing_and_supportive_services/chain_factsheet3.pdf

[2] Academy of Nutrition and Dietetics (formerly American Dietetic Association). HIV/AIDS Nutrition Evidence Analysis Project at http://www.adaevidencelibrary.com/conclusion.cfm?conclusion_statement_id=250707 Accessed 29 July 2012.

[3] Aidala A., Yomogida M., and the HIV Food & Nutrition Study Team (2011);
Singe AW,Weiser SD, McCoy, SI. Does Food Insecurity Undermine Adherence to Antiretroviral Therapy? A Systematic Review. AIDS Behav (2015) 19:1510–1526.

[4] Ibid.

[5] Anema A, Chan K, Yip B, Weiser S, Montaner JSG, Hogg RS. Impact of food insecurity on survival among HIV-positive injection drug users receiving antiretroviral therapy in a Canadian cohort. 141st APHA Annual Meeting, Nov. 2-6, 2013. Boston, MA. Abstract #: 290277

[6] Aidala A., Yomogida M., and the HIV Food & Nutrition Study Team (2011).

[7] Gurvey J, Rand K, Daugherty S, Dinger C, Schmeling J, Laverty N. Examining Health Care Costs Among MANNA Clients and a Comparison Group. J Prim Care Community Health. (2013) 4:311-317

[8] Ibid.

[9] Rabeneck L, Palmer A, Knowles JB, Seidehamel RJ, Harris CL, Merkel KL, Risser JMH, Akrabawi SS. A randomized controlled trial evaluating nutrition counseling with or without oral supplementation in malnourished HIV-infected patients. J Am Diet Assoc. (1998) 98: 434-438;Schwenk A, Steuck H, Kremer G. Oral supplements as adjunctive treatment to nutritional counseling in malnourished HIV-infected patients: randomized controlled trial. Clinical Nutrition (1999) 18(6): 371-374.

[10] M. S. Cohen *et al.*, Prevention of HIV-1 Infection with Early Antiretroviral Therapy. N. Engl. J. Med.(2011) 365, 493-505 . HPTN 052

[11] Palar K, Laraia B, Tsai A, Weiser SD. Food insecurity is associated with sexually transmitted infections and HIV serostatus among low income adults in the National Health and Nutrition Examination Survey (NHANES) (1999-2010). Presented at the American Public Health Association 141st Annual Meeting, Boston, MA, November 5, 2013.

[12] Aidala A, Yomogida M, Vardy Y & the Food & Nutrition Study Team. Food and Nutrition Services, HIV Medical Care, and Health Outcomes. New York State Department of Health: Resources for Ending the Epidemic, 2014. Available at

13 Weiser SD, Frongillo EA, Ragland K, Hogg RS, Riley ED, Bangsberg DR. Food insecurity is associated with incomplete HIV RNA suppression among homeless and marginally housed HIV-infected individuals in San Francisco. J Gen Intern Med. (2009) 24(1):14-20.

FIRST FOCUS

MAKING CHILDREN & FAMILIES THE PRIORITY

1110 Vermont Avenue NW, Suite 900 | Washington, DC 20005 | T: 202.657.0670 | F: 202.657.0671 | www.firstfocus.org

BRUCE LESLEY, PRESIDENT, FIRST FOCUS

STATEMENT FOR THE RECORD

U.S. HOUSE OF REPRESENTATIVES COMMITTEE ON APPROPRIATIONS SUBCOMMITTEE ON LABOR, HEALTH & HUMAN SERVICES, EDUCATION, AND RELATED AGENCIES

April 15, 2016

Thank you for the opportunity to submit a statement for the record on the Fiscal Year 2017 (FY 17) Labor, Health and Human Services and Education Appropriations bill. On behalf of First Focus, I respectfully request you fund the following critical programs that greatly benefit children and families accordingly:

U.S. Department of Health and Human Services

1. The Runaway and Homeless Youth Act (RHYA) programs, **$165,000,000**;
2. Child Care and Development Block Grant (CCDBG), **$3,961,000,000**;
3. Head Start and Early Head Start, **$9,602,095,000**;
4. Childhood Lead Poisoning Prevention Program, **$35,000,000**; and
5. Healthy Homes Program, **$35,000,000**

U.S. Department of Education

1. McKinney-Vento Education for Homeless Children and Youth (EHCY) program, **$85,000,000**

INVESTING IN KIDS

First Focus is a bipartisan children's advocacy organization dedicated to making children and families the priority in federal policy and budget decisions. Our organization is committed to ensuring that all of our nation's children have equal opportunity to reach their full potential.

There are more than 200 distinct child and family programs and the Appropriations Subcommittee on Labor, Health & Human Services and Education has jurisdiction over many. Every year for the last ten years, First Focus has published an annual *Children's Budget* book that offers a detailed analysis and guide to federal spending levels and priorities on children and families.

Last year's ***Children's Budget 2015*** showed that the share of federal spending dedicated to children fell to just 7.89 percent, down from its highest level of 8.5 percent in 2010. Consequently, the federal share of discretionary spending dedicated to children has dropped by 7.2 percent over the last five years.

On an inflation-adjusted basis, federal discretionary spending on children has dropped by 11.6 percent between 2010 and 2015. Discretionary funding dedicated to children's health, education, child welfare, training, safety, and nutrition have all decreased, even without adjusting for inflation.

We ask that you reverse this trend and increase funding for these critical programs under your subcommittee's jurisdiction that benefit children.

THE RUNAWAY AND HOMELESS YOUTH ACT PROGRAMS
Agency: **U.S. Department of Health and Human Services**
FY 17 Request: **$165,000,000**

National estimates have found that 1.3 to 1.7 million youth experience one night of homelessness a year with 550,000 youth being homeless for a week or longer. As a result of these significant numbers, we request $165 million for the Runaway and Homeless Youth Act programs.

The funding would help prevent trafficking, identify survivors, and provide services to runaway, homeless and disconnected youth. Previous funding has laid the foundation for a national system of services for our most vulnerable young people who are at risk of becoming or have already been victims of exploitation and trafficking, abuse, familial rejection, unsafe communities, and poverty.

CHILD CARE AND DEVELOPMENT BLOCK GRANT
Agency: **U.S. Department of Health and Human Services**
FY 17 Request: **$3,961,000,000**

There is great promise in the reforms included in the bipartisan reauthorization of CCBDG. Unfortunately, there is still insufficient funding to implement these reforms, which are designed to achieve the important goals of ensuring the health and safety of child care, improve quality of care, and make it easier for families to obtain and retain child care assistance. Without a significant increase in CCDBG funding, states may be forced to cut the number of children receiving child care assistance or reduce payment rates for already low-paid child care providers. We request $3.961 billion for the Child Care and Development Block Grant to make high-quality child care more available and affordable for the families who need it most.

HEAD START AND EARLY HEAD START
Agency: **U.S. Department of Health and Human Services**
FY 17 Request: **$9,602,095,000**

Head Start and Early Head Start play an important role in providing vulnerable children under age five with the comprehensive care and education that they need to prepare for school. At the current funding level, Head Start can serve only slightly over two out of five eligible preschoolers. Early Head Start serves just 4 percent of eligible infants and toddlers. Proposals for more Head Start programs to provide full-school-day, full-school-year services would help to ensure that our lowest-income children receive a strong early learning experience. We request $9,602,095,000 for Head Start and Early Head Start to improve the outcomes of our earliest learners and future generations.

CHILDHOOD LEAD POISONING PREVENTION PROGRAM
Agency: U.S. Department of Health and Human Services
FY 17 Request: $35,000,000

Current lead poisoning surveillance is limited to 29 states and the District of Columbia due to severe funding cuts. National lead poisoning surveillance would enable communities to identify lead poisoning outbreaks to prevent catastrophes such as that of Flint, Michigan.

The Centers for Disease Control and Prevention is the only agency that houses the information regarding where and when children are poisoned, maintaining it through a surveillance system that monitors blood test results for 4 million children each year. The U.S. Department of Housing and Urban Development (HUD), as well as state and local health and housing agencies, rely on this surveillance system to target funds and enforcement to the highest-risk areas. The recent funding cuts have geographically restricted the surveillance effort and hurt local health departments in their prevention and case management efforts. We request $35 million for the Childhood Lead Poisoning Prevention program.

HEALTHY HOMES PROGRAM
Agency: U.S. Department of Health and Human Services
FY 17 Request: $35,000,000

The Healthy Homes Program helps children and families avoid the effects multiple childhood diseases and injuries in the home. This initiative takes a comprehensive approach to these activities by focusing on housing-related hazards in a coordinated effort, rather than addressing a single hazard at a time.

Through robust grants, enforcement efforts, research, and outreach, the Healthy Homes program has been instrumental in achieving a 70 percent reduction in childhood lead poisoning cases since the early 1990s. In addition to saving lives and improving the health of children, this program has saved the nation billions of dollars by increasing productivity, decreasing medical and special education costs, and potentially reducing criminal activity. In order to continue this progress, we request $35 million for the Healthy Homes program.

MCKINNEY-VENTO EDUCATION FOR HOMELESS CHILDREN AND YOUTH PROGRAM
Agency: U.S. Department of Education
FY 17 Request: $85,000,000

Public schools identified a record 1,301,239 homeless children and youth in 2013-2014. This is a 7 percent increase from the previous year, and a 100 percent increase since 2006-2007. With this rise in homeless children and youth, we request $85 million to implement the McKinney-Vento Act's Education for Homeless Children and Youth program. This amount was authorized in the recently enacted Every Student Succeeds Act which is an increase of $10 million.

This funding would provide services to and identify homeless children and youth, who are at high risk of human trafficking. The EHCY program is effective in mitigating the devastating effects of child and youth homelessness. With the support of EHCY program grants, local education agencies have provided identification, enrollment and transportation assistance, as well as academic support and referrals for basic services. The EHCY program has given homeless children and youth the extra support they need to enroll and succeed in school.

Testimony of the Nursing Community
Prepared for the U.S. House Appropriations Subcommittee on Labor, Health and Human Services, and Education, and Related Agencies

U.S. Department of Health and Human Services
Health Resources and Services Administration

National Institutes of Health

April 15, 2016

Submitted by Suzanne Miyamoto, Convener of the Nursing Community

The Nursing Community is a coalition comprised of 62 national professional nursing associations that builds consensus and advocates on a wide spectrum of healthcare issues surrounding education, research, and practice. These organizations are committed to promoting America's health through the advancement of the nursing profession. Collectively, the Nursing Community represents over one million Registered Nurses (RNs), Advanced Practice Registered Nurses (including certified nurse-midwives (CNMs), nurse practitioners (NPs), clinical nurse specialists (CNSs), and certified registered nurse anesthetists (CRNAs)), nurse executives, nursing students, faculty, researchers, and other nurses with advanced degrees. For Fiscal Year (FY) 2017, our organizations respectfully request **$244 million for the Health Resources and Services Administration's (HRSA) Nursing Workforce Development programs** (authorized under Title VIII of the *Public Health Service Act* [42 U.S.C. 296 et seq.]) and **$157 million for the National Institute of Nursing Research** (NINR), one of the Institutes and Centers within the National Institutes of Health (NIH).

Title VIII Programs: Responding to the Needs of America's Patients through Nursing Care
As integral members of the healthcare team, nurses collaborate with other professions and disciplines to improve the quality of America's healthcare system. The reach of their care is vast: they offer essential patient care in a variety of settings, including hospitals, long-term care facilities, community centers, state and local health departments, schools, workplaces, and patient homes. RNs comprise the largest group of health professionals with over three million licensed providers in the country.[1] A constant focus must be placed on education, recruitment, and retention to ensure a stable workforce, particularly in geographic regions that will continue

[1] National Council of State Boards of Nursing. (2016). *Active RN Licenses: A profile of nursing licensure in the U.S. as of January 23, 2016*. Retrieved from: https://www.ncsbn.org/6161.htm.

to experience health provider shortages in the coming years. A significant investment must be made in the education of new nurses to provide the nation with the services it demands.

For over 50 years, the Nursing Workforce Development programs, authorized under Title VIII of the Public Health Service Act, have helped to build the supply and distribution of qualified nurses to meet our nation's healthcare needs. Title VIII programs bolster nursing education at all levels, from entry-level preparation through graduate study, and provide support for institutions that educate nurses for practice in rural and medically underserved communities. Today, the Title VIII programs are essential to ensuring the demand for nursing care is met. Title VIII programs target specific aspects of America's nursing workforce and patient populations that require federal support in order to ensure efficient and effective delivery of healthcare services.

For example, according to HRSA, there were over 61.2 million individuals living in primary care Health Professional Shortage Areas as of December 2015.[2] Title VIII programs provide graduate students and practicing nurses exposure to caring for underserved communities such as these, thus helping to bolster recruitment and retention in these areas. In academic year 2014-2015, the Title VIII Advanced Education Nursing Traineeships supported 3,008 students, of which 72% were trained in primary care,[3] and the Title VIII Nurse Anesthetist Traineeships supported 3,229 students, of which 64% were trained in Medically Underserved Areas.[4] Moreover, the U.S. Bureau of Labor Statistics' projection that employment of CRNAs, CNMs, and NPs is expected to grow 31% between 2012 and 2022.[4] These programs strengthen the supply of these clinicians.

Additionally, the Title VIII NURSE Corps Loan Repayment and Scholarship Programs assist students who agree to serve at least three years in facilities experiencing a critical shortage of providers.[4] Last year, 55% of the Loan Repayment Program recipients extended their service contracts to work in these facilities beyond the required three years.[4] Clearly, these programs are instrumental to connecting current and future providers to patient populations most in need.

---

[2] U.S. Health Resources and Services Administration. (2016). *Designated Health Professionol Shortage Areas Statistics*. Retrieved from: https://ersrs.hrsa.gov/ReportServer?/HGDW_Reports/BCD_HPSA/BCD_HPSA_SCR50_Qtr_Smry_HTML&rc:Toolbar=false.

[3] U.S. Department of Health and Human Services. (2016). *Health Resources and Services Administration Fiscal year 2017 Justification of Estimates for Appropriations Committees*. Retrieved from: http://www.hrsa.gov/about/budget/budgetjustification2017.pdf.

[4] U.S. Bureau of Labor Statistics. (2014). Occupational Outlook Handbook. Registered Nurses. Retrieved from: http://www.bls.gov/ooh/healthcare/registered-nurses.htm.

America's aging population is another sector that will require additional providers. According to the U.S. Census Bureau, it is estimated that by year 2050, the number of people in the U.S. age 65 and older will reach 83.7 million (nearly one-quarter of the projected population).[5] Rising rates of chronic illness, coupled with an expanding population, will necessitate a cadre of nurses to care for these individuals. The Title VIII Comprehensive Geriatric Education program is designed to meet this call. In academic year 2014-2015 alone, there were 22,743 students and trainees supported through these grants. These individuals are the future caregivers to elderly Americans. Funding through this program was utilized to prepare faculty members, develop and disseminate geriatric curriculum, and provide traineeships for students pursuing advanced education nursing degrees in gero-psychiatric nursing, long-term care, and other nursing specialties centered on caring for elderly populations.

The Nursing Community respectfully requests $244 million for the Nursing Workforce Development programs in FY 2017.

National Institute of Nursing Research: Foundation for Evidence-Based Care

The care that nurses provide must be rooted in evidence. As one of the 27 Institutes and Centers at the NIH, NINR funds research that lays the groundwork for evidence-based nursing practice. NINR examines ways to improve care models to deliver safe, high-quality, and cost-effective health services to the nation. Our country must look toward the prevention aspect of health care as the vehicle for saving our system from further financial burden, and the work of NINR embraces this endeavor through research related to care management of patients during illness and recovery, reduction of risks for disease and disability, promotion of healthy lifestyles, enhancement of quality of life for those with chronic illness, and care for individuals at the end of life. NINR addresses these challenges through its Strategic Plan, which 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 qualify of life; and end-of-life and palliative care science.[6]

In addition, NINR recognizes the need for improving global health and promotes research to reduce communicable diseases and improve public health and wellness such as maternal-newborn care. Moreover, NINR allots a generous portion of its budget towards training new nursing scientists, thus helping to sustain the longevity and success of nursing research.

---

[5] U.S. Census Bureau. (2014). *An Aging Nation: The Older Population in the United States*. Retrieved from: https://www.census.gov/prod/2014pubs/p25-1140.pdf.

[6] National Institutes of Health. National Institute of Nursing Research. *Implementing NINR's Strategic Plan: Key Themes*. Retrieved from: http://www.ninr.nih.gov/aboutninr/keythemes#.VRVhGWZ_SSU.

Training programs at NINR develop future nurse researchers, many of whom also serve as faculty in our nation's nursing schools.

The Nursing Community respectfully requests $157 million for the NINR in FY 2017. The Ad Hoc Group for Medical Research requests at least $34.5 billion for NIH in 2017, and the request level of $157 million for NINR denotes the same percentage increase for NIH applied to NINR.

Members of the Nursing Community Submitting this Testimony

Academy of Medical-Surgical Nurses
American Academy of Ambulatory Care Nursing
American Academy of Nursing
American Assembly for Men in Nursing
American Association of Colleges of Nursing
American Association of Critical-Care Nurses
American Association of Heart Failure Nurses
American Association of Neuroscience Nurses
American Association of Nurse Anesthetists
American Association of Nurse Assessment Coordination
American Association of Nurse Practitioners
American Association of Occupational Health Nurses
American College of Nurse-Midwives
American Nephrology Nurses' Association
American Nurses Association
American Organization of Nurse Executives
American Pediatric Surgical Nurses Association
American Psychiatric Nurses Association
American Society for Pain Management Nursing
American Society of PeriAnesthesia Nurses
Association for Radiologic and Imaging Nursing
Association of Community Health Nursing Educators
Association of Nurses in AIDS Care
Association of Pediatric Hematology/Oncology Nurses
Association of Public Health Nurses
Association of Rehabilitation Nurses
Association of Women's Health, Obstetric and Neonatal Nurses
Commissioned Officers Association of the U.S. Public Health Service
Dermatology Nurses' Association
Emergency Nurses Association
Gerontological Advanced Practice Nurses Association
Hospice and Palliative Nurses Association
Infusion Nurses Society
International Association of Forensic Nurses

International Society of Psychiatric-Mental Health Nurses
National Association of Clinical Nurse Specialists
National Association of Neonatal Nurse Practitioners
National Association of Neonatal Nurses
National Association of Nurse Practitioners in Women's Health
National Association of Pediatric Nurse Practitioners
National Black Nurses Association
National Council of State Boards of Nursing
National Gerontological Nursing Association
National League for Nursing
National Nursing Centers 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
Public Health Nursing Section, American Public Health Association
Society of Urologic Nurses and Associates
The Quad Council of Public Health Nursing Organizations
Wound, Ostomy and Continence Nurses Society

Harold Wimmer
National President and CEO
American Lung Association
202-785-3355
Erika.Sward@Lung.org

FY 2017
American Lung Association
U.S. House of Representatives Committee on Appropriations
Subcommittee on Labor, Health and Human Services, and Education
Department of Health and Human Services

Centers for Disease Control and Prevention (CDC)
Increase CDC funding to $7.8 billion
Office on Smoking and Health – $220 million
National Asthma Control Program– $30.596 million
Climate and Health Program – $18.613 million
Environment and Health Tracking Network – $35 million
Tuberculosis Programs – $243 million
CDC influenza planning and response – $187.558 million
NIOSH – $522.3 million
Prevention and Public Health Fund – Please Protect the Fund

National Institutes of Health (NIH)

The American Lung Association is pleased to submit its recommendations for Fiscal Year 2017 (FY17) 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 $34.5 billion for the National Institute of Health (NIH). We need sustained and robust investments for NIH so that the promise of biomedical research can be achieved. While our focus is on lung disease research, we support robust, sustained and predictable investments in research funding across the entire NIH with particular emphasis on the National Cancer Institute, the National Heart, Lung and Blood Institute, the National Institute of Allergy and Infectious Diseases, the National Institute of Environmental Health Sciences, the National Institute of Nursing Research, the National Institute on Minority Health & Health Disparities, the National Institute on Drug Abuse and the Fogarty International Center.

Lung Disease
Lung disease is the third highest killer in America. It takes the lives of almost 419,000 Americans each year, and is responsible for one in every six deaths. It has been estimated that more than 33 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 programs that provide resources for those who want to quit smoking, support groups for lung cancer patients, and classes that educate people on ways to avoid asthma attacks. 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 224,390 new cases of lung cancer will be diagnosed in 2016, and over 156,000 Americans will die from the disease – 85,710 in men and 70,542 in women. Survival rates for lung cancer tend to be lower than those of 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. Personalized and targeted therapies hold tremendous potential in the fight against lung cancer. As the result of previous investments in biomedical research, in 2015, the Food and Drug Administration approved seven new medications for patients with metastatic lung cancer. The American Lung Association thanks the Committee for its 5 percent increase in funding for NIH, including funds for the President's Precision Medicine Initiative with its ALCHEMIST and Lung-MAP trials that target lung cancer. **We ask the Committee to continue to build on this momentum by increasing funding for the National Institutes of Health to $34.5 billion in Fiscal Year 2017.**

Tobacco Use
The use of tobacco is the number one preventable cause of death in the United States. It kills approximately half a million people every year. 40 million American adults smoke and 4.7 million children use tobacco products. Annual health care and lost productivity costs total $332 billion in the U.S. each year. Each day, over 2,500 kids under 18 years of age try their first cigarette and close to 600 kids become new, regular daily smokers.

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 $220 million be appropriated to OSH for FY17.**

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 five 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

24 million Americans have asthma, including 6.3 million children. It is highly prevalent and a costly disease. The nation is making progress to combat against asthma but this advancement can only continue with sustained investment. Asthma prevalence rates are over 45 percent higher among African Americans than whites. Asthma costs our healthcare system over $50.1 billion annually and indirect costs from lost productivity add another $5.9 billion, for a total of $56 billion dollars annually.

The American Lung Association thanks the Committee for its increase in FY16 and **asks to appropriate $30.596 million to the CDC's National Asthma Control Program (NACP) in FY2017.** 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 23 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 27 states and the District of Columbia.

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

Chronic Obstructive Pulmonary Disease (COPD)

COPD is the third leading cause of death in the U.S. More than 24 million U.S adults had evidence of impaired lung function, indicating an under diagnosis of COPD. In 2013, 145,575 people in the U.S. died of COPD, representing one COPD death every 4 minutes. The American Lung Association also asks the Committee to continue its support of the National Heart, Lung and Blood Institute working with the 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.**

Pneumonia and Influenza

In 2013, there were a combined 56,979 deaths due to pneumonia and influenza combined. While other infectious diseases may receive much more public attention, a moderate flu epidemic could result in hundreds of thousands of deaths in the U.S. To prepare for a potential pandemic, **the American Lung Association supports funding the federal CDC Influenza efforts of at least $187.558 million.**

Tuberculosis (TB)
TB, an airborne infectious disease, is now the leading global infectious killer, ahead of HIV/AIDS, causing 1.5 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.

Drug resistant TB poses a particular challenge to TB control due to the high costs of treatment and intensive health care 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. The U.S. had 17 cases of extensively XDR- TB between 2008 and 2015.

Funding for CDC's national TB program has been cut back to the FY2005 level. We are deeply concerned that this funding level is eroding state TB programs and leaving communities vulnerable to TB, including drug resistant TB. **We request that Congress increase funding for tuberculosis programs at CDC to $243 million for FY 2017.**

Impact of Climate Change on Lung Health
CDC's Climate and Health Program is the only HHS program devoted to identifying the risks and develop effective responses to the health impacts of climate change, including worsening air pollution; diseases that emerge in new areas; stronger and longer heat waves; 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 $10 million for the Center for Disease Control and Prevention's Climate and Health Program**.

Conclusion
Lung disease remains a growing problem in the United States and is leading the nation as the third highest killer. There has 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. Significant strides must be taken to combat the lung disease. The level of support this committee approves for lung disease programs should be reflective of the urgency and magnitude 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. The Lung Association is appreciative of your support and we thank you for your consideration of our recommendations.

HOUSE COMMITTEE ON APPROPRIATIONS
SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES, EDUCATION AND RELATED AGENCIES

TESTIMONY BY THE HUMANE SOCIETY OF THE UNITED STATES AND HUMANE SOCIETY LEGISLATIVE FUND ON THE FY 2017 BUDGET – NATIONAL INSTITUTES OF HEALTH

April 15, 2016

Contact: Sara Amundson, Executive Director,
Humane Society Legislative Fund
2100 L Street NW, Washington, DC 20037
samundson@hslf.com; (202)676-2341

Kate Wall, Senior Federal Legislative Specialist,
The Humane Society of the United States
2100 L Street NW, Washington, DC 20037
kwall@humanesociety.org; (202)955-3672

On behalf of The Humane Society of the United States (HSUS) and the Humane Society Legislative Fund (HSLF), we appreciate the opportunity to provide testimony on our top NIH funding priorities for the House Labor, Health and Human Services, Education and Related Agencies Appropriations Subcommittee in Fiscal Year 2017.

RETIREMENT OF FEDERALLY-OWNED CHIMPANZEES BY THE NATIONAL INSTITUTES OF HEALTH

The HSUS and HSLF would like to thank the committee for all their hard work to ensure that the National Institutes of Health (NIH) retires government-owned chimpanzees from laboratories to sanctuary. Since their announcement in June of 2013, when the NIH laid out their plans to retire all but 50 government-owned chimpanzees to sanctuary, the agency has decided to retire all chimpanzees - including the group of 50 reserve chimpanzees. There are currently approximately 300 chimpanzees cared for by the government who need to be moved from laboratories to the National Chimpanzee Sanctuary.

Chimpanzees should be moved as quickly as possible to sanctuary, since it is in their best interest for their welfare as well as good for taxpayers. At Chimp Haven, the National Chimpanzee Sanctuary, chimpanzees are the sole focus of the facility and its staff. There, chimpanzees receive the very best care possible, including access to expansive outdoor habitats, large social groups and regular and varying enrichment. Accredited sanctuaries provide the highest welfare standards for chimps at a lower cost to taxpayers than housing chimpanzees in barren labs. It is estimated that transferring the government-owned chimpanzees who are slated for retirement from the laboratories where they are currently housed to the national sanctuary would save taxpayer dollars for care and maintenance costs. For these reasons, it is imperative that the NIH move the remaining government-owned chimpanzees to sanctuary as soon as possible.

To facilitate this transfer, the National Chimpanzee Sanctuary will need to expand, which will be a significant expense for the sanctuary. There is no doubt that relief of this financial strain would expedite the faster movement of the chimpanzees to sanctuary.

We respectfully request that the Subcommittee continue to work with the NIH to ensure the remainder of the government-owned chimpanzees housed in laboratories are sent to sanctuary in a timely manner.

THE NATIONAL CENTER FOR ADVANCING TRANSLATIONAL SCIENCES

The National Center for Advancing Translational Sciences (NCATS) is one of 27 Institutes and Centers (ICs) at the NIH. Established to transform and accelerate the translational research process, NCATS is all about getting more treatments to more patients more quickly. The Center complements other NIH ICs, the private sector and the nonprofit community; rather

than concentrating on specific diseases, NCATS focuses on what is common among them. The Congress awarded $53,000,000 over the president's budget for Fiscal Year 2016.

Translation is the process of turning observations in the laboratory, clinic and community into interventions that improve the health of individuals and the public — from diagnostics and therapeutics to medical procedures and behavioral changes.

Translational science is the field of investigation focused on understanding the scientific and operational principles underlying each step of the translational process.

Bridging the Gap

Several thousand genetic diseases affect humans, of which only about 500 have any treatment. A novel drug, device or other intervention can take about 14 years and cost $2 billion or more to develop, and about 95 percent never make it past clinical trials. Even when a new drug or other intervention is developed and shown to be effective in clinical trials, many years may pass before all patients who could benefit from it are identified and treated.

Here are some areas the animal protection community and industry have supported:

- Tissue Chip for Drug Screening (Tissue Chip) initiative. This partnership with the Defense Advanced Research Projects Agency and the Food and Drug Administration (FDA) is designed to develop 3-D human tissue chips that model the structure and function of human organs, such as the lung, liver and heart, and then combine these chips into an integrated system that can mimic complex functions of the human body.

- Toxicology in the 21st Century (Tox21) initiative. Tox21 is a collaborative effort among NIH — including NCATS and the National Toxicology Program at the National Institute of Environmental Health Sciences — the Environmental Protection Agency and the FDA. Through Tox21, researchers are testing 10,000 drugs and environmental chemicals for their potential to affect molecules and cells in ways that can cause health problems. The compounds undergo testing in NCATS' high-speed robotic screening system.

We respectfully request the Subcommittee request an update from NCATS on the plans for translational work to ultimately eliminate the use of animals in chemical testing and drug development.

House Committee on Appropriations
Subcommittee on Labor HHS
The Humane Society of the United States and Humane Society Legislative Fund
on the FY 2017 Budget
April 15, 2016

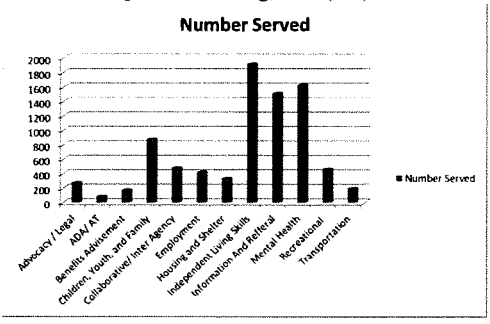
We appreciate the opportunity to share our views for the Labor, Health and Human Services, Education and Related Agencies Appropriations Act for Fiscal Year 2017.

Name Michael I. Kochler
Title Employment Services Coordinator/ Statewide Systems Advocate
Institutional Affiliation: Independent Living, Inc., 5 Washington Terrace, Newburgh, NY 12550

I, Michael I. Kochler, Employment Services Coordinator/ Statewide Systems Advocate at Independent Living, Inc., 5 Washington Terrace, Newburgh, NY 12550, am writing to support the National Council on Independent Living's request for Congress to reaffirm your commitment to the more than 57 million Americans disabilities by increasing funding in the HHS appropriations for Centers for Independent Living (CILs). I am asking that you increase funding by $200 million, for a total of $301 million for the Independent Living line item in FY 2017.

CILs, such as Independent Living, Inc, are cross-disability, non-residential, community-based, nonprofit organizations that are designed and operated by individuals with disabilities. CILs are unique in that they are directly governed and staffed by people with all types of disabilities, including people with mental, physical, sensory, cognitive, and developmental disabilities. Each of the 365 federally funded centers provides five core services: information and referral, individual and systems advocacy, peer support, independent living skills training, and transition services, which were added with the passage of the Workforce Innovation and Opportunity Act (WIOA). From 2012-2014, CILs provided the core services to nearly 5 million people with disabilities, and provided additional services such as housing assistance, transportation, personal care attendants, and employment services to hundreds of thousands of individuals.

In 2014 Independent Living, Inc. (ILI) served 8316 people with disabilities in three centers located in Orange and Sullivan Counties in New York State. As the accompanying graph shows, those services were provided in the four core areas: Advocacy / Legal, Independent Living Skills, Information and Referral, and Mental Health / Peer Services as well as eight additional areas. In 2015 Transition Supports were added thanks to a program of the NY State Office of People with Developmental Disabilities (OPWDD) – prior to the WIOA mandate.



With the aging of America and the issues that go along with a longer life, as well as the medical advances that allow more individuals with disabilities to participate more fully in society, the demand for these services – and others - will only increase.

Transition services were added as a fifth core service with the 2014 reauthorization of the Rehabilitation Act within the Workforce Innovation and Opportunity Act. Transition services include the transition of individuals with significant disabilities from nursing homes and other institutions to home and community-based residences with appropriate supports and services, assistance to individuals with significant disabilities at risk of entering institutions to remain in the community, and the transition of youth with significant disabilities to postsecondary life. This core service is vital to achieving full participation for people with disabilities.

Every day, CILs are fighting to ensure that people with disabilities gain and maintain control of their lives. We know that this cannot occur when people reside in institutional settings. Opponents of deinstitutionalization say that allowing people with disabilities to live in the community will result in harm. We know that the 13,030 people with disabilities who CILs successfully transitioned out of nursing homes and institutions from 2012-2014 prove otherwise. Additionally, when services are delivered in an individual's home, the result is a tremendous cost savings to Medicaid, Medicare, and states. Community-based services enable people with disabilities to become less reliant on long-term government supports, and they are significantly less expensive than nursing home placements. We are grateful that Congress demonstrated their understanding and support for community-based services when WIOA was passed and transition was added as a fifth core service. During the period 2012 - 2014, prior to transition being added as a core service, CILs transitioned 13,030 people with disabilities from nursing homes and other institutions into the community.

Since 1989 ILI has made transitioning individuals from institutions to the community a priority. In 2015 Independence Square, a 74 unit apartment building opened, built largely with funding secured by ILI and our supporters. It provides accessible housing for families and individuals from many different cultures, at different stages in their lives. This includes 14 units set aside for individuals being served by the NY State Office of People with Developmental Disabilities (OPWDD). All 14 units are now occupied by people that were transitioned out of group homes into an independent, fully integrated apartment building in the community.

In an example of ILCs promoting community living and working together to advocate for our consumers a 5-month battle has been waged on behalf of a young woman attempting to return to her own home. In June 2015 she moved from a facility into her own apartment for the first time. In November she became ill and required hospitalization. When she was due to be released, in spite of her desire to return home, and the responsible state agency's agreement in principal, the transition was blocked due to staffing and funding problems. Then they sited rules regarding housing her overnight aide. OPWDD threatened to remove the consumer from the apartment program and keep her in a facility once again. Advocates from ILI and Westchester Independent Living Center (WILC) partnered to get the Department of Social Services to intervene on behalf of the consumer. OPWDD held the apartment open and allowed for a temporary adaptation to the apartment until a more suitable apartment is found. The young woman finally returned *to her own home* in April 2016. A larger apartment has been secured (she moves in May) and Social Services is working with our advocates to ensure that the funds for her apartment and aid are in place.

Since transition services were added as a core service, the need for funding is critical. Moreover, CILs need additional funding to restore the devastating cuts to the Independent Living program, make up for inflation costs, and address the increased demand for independent living services. In 2016, the Independent Living Program is receiving $2.5 million less in funding than it was in 2010. It is simply not possible to meet the increasing demand for services and effectively provide transition services without additional funding. Increased funding should be reinvested from the billions currently spent to keep people with disabilities in costly Medicaid nursing homes and institutions and out of mainstream society.

In New York State alone those savings have amounted to nearly $1.9 *billion* between 2001 and 2015. And that was at a cost of just over $101 million.

NYS INDEPENDENT LIVING CENTERS
DEINSTITUTIONALIZATION COST SAVINGS
STATEWIDE REPORT *
October 2001 - September 2015

Contract Period	Institutional Preventions	Institutional Terminations	Deinstitutionalization Savings	NYS Funds Distributed for Reporting ILCs	Value Added ***
2001-2003 **	1,216	281	$119,222,981	$8,714,698	$110,508,283
2003-2004	1,331	288	$115,525,533	$4,099,991	$111,425,542
2004-2005	1,605	222	$131,116,411	$3,452,100	$127,664,311
2005-2006	1,361	204	$110,148,680	$3,615,789	$106,532,891
2006-2007	1,462	231	$117,719,426	$3,967,122	$113,752,304
2007-2008	1,598	304	$118,632,477	$9,036,056	$109,596,421
2008-2009	2,191	294	$124,095,825	$9,104,974	$114,990,851
2009-2010	2,083	219	$128,793,175	$9,591,682	$119,201,493
2010-2011	2,099	223	$128,046,157	$9,845,804	$118,200,353
2011-2012	2,303	869	$199,220,268	$9,845,804	$189,374,464
2012-2013	2,881	316	$192,054,457	$9,668,545	$182,385,912
2013-2014	2,913	692	$224,571,234	$10,211,725	$214,359,509
2014-2015	3,738	346	$187,749,351	$10,588,755	$177,160,596
TOTAL	26,781	4,489	$1,896,895,975	$101,743,045	$1,795,152,930

*** From 10/01-9/07 ILC participation was voluntary. Not all ILCs contributed data for each report period.**
*** Starting with 10/07-9/08, ILC participation was required, but not all ILCs had data to report for each report period.**
**** Project started SFY 02-03 and included cumulative data for SFY 01-02.**
***** Deinstitutionalization Savings minus NYS Funds Distributed for Reporting ILCs equals Value Added.**

Centers for Independent Living play a crucial role in the lives of people with disabilities, and their staff work tirelessly to ensure that people with disabilities have a real choice in where and how they live, work, and participate in the community. Additionally, CILs are an excellent service and a bargain for America, keeping people engaged with their communities and saving taxpayer money. NCIL is dedicated to increasing the availability of the invaluable and extremely cost-effective services CILs provide, and they have submitted written testimony with a similar request. I strongly support NCIL's testimony.

Robert McKown, President, Board of Directors
Charlene Hipes, Chief Operating Officer
Alliance of Information and Referral Systems (AIRS)

Chairman Cole, Ranking Member DeLauro;

On behalf of the Alliance of Information and Referral Systems (AIRS), we thank you for the opportunity to offer testimony in support of the Department of Health and Human Services' proposed increase of $10 million for the Older Americans Act Title III(B) Home and Community-Based Supportive Services program within the Administration for Community Living, as well as testimony against the Department of Health and Human Services' proposed cuts to the Low-Income Home Energy Assistance Program and Community Services Block Grant program within the Administration for Children and Families.

AIRS, with more than 1,000 members from across the United States and Canada, is the organization which brings people and services together. More specifically, we are the lead national agency which developed the professional standards that are a part of thousands of quality Information and Referral (I&R) programs operated under the Older Americans Act. AIRS members answer more than 28 million calls per year for help about community, social and health services.

Older Americans Act Title III(B) Home and Community-Based Supportive Services

I&R services provided under Title III(B) of the Older Americans Act are critical to providing older adults in need with assistance in every community in this nation. I&R organizations have databases of programs and services and disseminate information through a variety of channels to individuals and communities. Older adults in need of critical services such as food, shelter, work and job training, and mental health support often do not know where to turn for support. I&R services provide answers.

Title III(B) also provides important supportive services such as home health care, transportation, and adult day care, programs to which AIRS members refer older adults. These programs are all in need of increased funding. The Administration has proposed an increase of $10 million for Title III(B) for FY 2017. Title III(B) has been level-funded for years and has not had funding restored from sequestration cuts in FY 2013. This increase would not fully restore funding, but it would help immensely to serve the growing need for these programs as our population ages.

Low-Income Home Energy Assistance Program

AIRS is very concerned about the Administration's proposed cut to the Low-Income Home Energy Assistance Program (LIHEAP). This 12 percent cut would reduce funding for LIHEAP by $390 million.

One AIRS member stated that in her county's elderly services program, two-thirds of her clients either have low enough incomes or have enough medical expenses to qualify for LIHEAP. When they receive shut-off notices, they call her I&R service for assistance; the I&R service refers the clients to one of a few possible resources for help. However, those resources do not have enough funding, so these older adults go without heating for days. In the winter, their pipes may break due to lack of heat, and it can take several days to start repairs. Meanwhile, these vulnerable adults have no heat or water.

This is only one local example; these issues happen nationally. Another AIRS member said that during the 4th quarter of 2015, 40% of the requests his agency received for heating or electric assistance were recorded as an unmet request, primarily because there were insufficient resources to assist households to pay arrearages. During the 3rd quarter, the unmet need requests neared 80%. Reducing funding for this important program would be a huge mistake and could harm many vulnerable populations, including frail older adults.

Community Services Block Grant

AIRS is also very concerned about the Administration's proposed cut to the Community Services Block Grant (CSBG). This cut would reduce funding for CSBG by $41 million.

Many I&R providers refer callers to the services provided under the CSBG, such as employment, education, housing assistance, nutrition, energy, emergency services, health, and substance abuse. These programs serve people of all ages. Reducing funding for this program would mean that many important services could be cut.

We thank you for your past and future support, and hope to continue to work with you through the appropriations process.

AMERICAN
PSYCHOLOGICAL
ASSOCIATION

Outside Witness Testimony

From the American Psychological Association (APA)

Re Fiscal Year 2017 Appropriations for

Labor, Health and Human Services and Education

U.S. House Committee on Appropriations

April 15, 2016

The APA is the largest scientific and professional organization representing psychology in the US: its membership includes over 123,000 researchers, educators, clinicians, consultants and students. Many programs in the Labor-HHS-Education bill impact science, education, and the populations served by clinical psychologists.

Department of Health and Human Services

National Institutes of Health (NIH): APA thanks this subcommittee for its leadership in securing $32.1 billion for NIH in the FY 2016 omnibus spending bill. As a member of the Ad Hoc Group for Medical Research, APA requests $34.5 billion for NIH in FY 2017. If this nation is to continue to accelerate the development of life-changing cures, pioneering treatments, and innovative prevention strategies, it is essential to sustain predictable increases in the NIH budget. Psychological scientists are supported by research grants or training programs in almost all of NIH's 27 institutes and centers. Behavioral research is critical to NIH's mission: the Institute of Medicine recently reaffirmed that over 50 percent of premature mortality in the U.S. is due to behaviors such as smoking, sedentary lifestyle, and alcohol and other drug consumption. Two areas of great scientific opportunity at NIH are research on Alzheimer's disease and related dementias, and health disparities research at the National Institute of Minority Health and Health Disparities.

Centers for Disease Control and Prevention (CDC)-- As a member of the CDC Coalition, APA supports an appropriation of at least $7.8 billion for core programs in FY 2017. APA strongly supports the President's request for increased funding for the National Injury Prevention and

Control Center, including $25 million for the National Violent Death Reporting System to allow for its expansion to all 50 states and DC, $20 million for core injury prevention programs, and $10 million for research into the causes and prevention of gun violence. As a member of the Friends of the National Center for Health Statistics, APA recommends $170 in budget authority for the agency. APA also supports the Administration's $30 million mandatory funding request for implementation and evaluation of comprehensive suicide prevention programs.

Agency for Healthcare Research and Quality (AHRQ) --APA requests that the Subcommittee support $364 million in budget authority—consistent with the president's discretionary funding request and FY 2015 level. AHRQ plays a critical role in the research continuum—helping patients get the most from new discoveries in basic and clinical research by improving health care delivery. For example, with the burgeoning opioid epidemic AHRQ research will help optimize delivery of behavioral and pharmacotherapies for the treatment of this devastating substance use disorder. In a variety of healthcare settings, AHRQ funded research is reducing medical errors and the incidence of Hospital Acquired Infections.

Health Resources and Services Administration (HRSA)--APA recommends that a portion of funding for the Maternal and Child Health Bureau be used to raise awareness of the availability of depression screening to pregnant women. Postpartum depression (PPD) and perinatal depression are commonly undiagnosed conditions associated with childbirth. APA encourages the subcommittee to fund the Melanie Blocker Stokes Act and to support incorporation of depression screening into the Title V programs administered by HRSA. We also encourage the Subcommittee to urge the Secretary to prioritize the issue of PPD by raising awareness, expanding research, and establishing grants for the operation and coordination of cost-effective services to afflicted women and their families.

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

APA recommends continued investments in the mental and behavioral health workforce, including $12 million for the interprofessional Graduate Psychology Education Program to increase the number of health service psychologists (including doctoral-level clinical, counseling and school psychologists) trained to provide integrated services to high-need underserved populations in rural and urban communities. This program supports the training of doctoral psychology students, interns and postdoctoral residents with other health professionals while they provide supervised mental and behavioral health services to underserved and vulnerable populations, including: children, older adults, veterans and their families, individuals with chronic illnesses, and victims of abuse and trauma. Recognizing the growing need for highly trained mental and behavioral health professionals to deliver evidence-based services to the rapidly aging population, APA encourages HRSA to invest in geropsychology training programs and to help integrate health service psychology trainees at Federally Qualified Health Centers.

APA supports the transfer of the Behavioral Health Workforce Education and Training Program to HRSA and the broadened target populations of people to be served. In light of the new competition that will be held in 2017, APA requests that eligible entities for this program include accredited programs that train Master's level social workers, psychologists, counselors, marriage and family therapists, doctoral psychology students and interns, as well as behavioral health paraprofessionals. APA is concerned about the uneven distribution of funds among specialties resulting from the initial grant competition in 2014 and therefore encourages HRSA to ensure that funding is distributed relatively equally among the participating health professions and to consider strategies such as issuing separate funding opportunity announcements for each participating health profession.

Substance Abuse and Mental Health Services Administration

APA strongly supports the President's FY17 budget proposal that supports increased initiatives to address prescription and opioid abuse. APA encourages Congress to adopt the President's FY17 request for a $500 million mental health initiative. This investment would increase access to early intervention programs for serious mental illness, expand the Community Behavioral Health Clinic demonstration, and provide substantial funding for suicide prevention in collaboration with the CDC. APA recommends funding the National Child Traumatic Stress Network (NCTSN) at the President's requested level of $46.9 million for the Network's efforts on behalf of the recovery of from trauma and violence. APA urges increased funding of the Minority Fellowship Program to reach a level of $20 million by 2020. While ethnic minorities represent 30% of the U.S. population and are projected to increase to 40% by 2025, only 23% of recent doctorates in psychology, social work and nursing were awarded to ethnic minorities. APA urges the continued support of the Minority AIDS Initiative funding which enhances and expands effective, culturally-competent HIV/AIDS-related behavioral services in minority communities.

APA strongly supports the Garrett Lee Smith Memorial Act programs--Campus Suicide Prevention, State and Tribal Youth Suicide Prevention and the Suicide Prevention Resource Center. These effective national programs help meet the mental and behavioral health needs of youth and young adults by increasing access to prevention, education, and outreach services to reduce suicide risk in states, tribes, and institutions of higher education. First authorized in 2004, the Garrett Lee Smith Memorial Act has supported 370 youth suicide prevention grants in 50 States, 48 Tribes or Tribal organizations, and 175 institutions of higher education.

Administration on Children and Families

We urge support for the existing funding level of $1.7 billion for the Social Services Block Grant for FY 2017.

Administration for Community Living Administration on Aging

We urge support of an additional $5 million authorized under the Elder Justice Act for the Long-Term Care Ombudsman Program, which was previously requested by the President. We urge

support for $197 million in funding for programs that support the vital role of family caregivers in providing care for older adults.

Department of Education

Institute of Education Sciences (IES) - As a member of the Friends of IES, APA requests $728 million for the Institute of Education Sciences which supports programs to evaluate the effects of federal and local education policies, gather and analyze data on student outcomes, develop and promote evidence-based practices for schools and teachers, and advance rigorous education research. APA also supports including increased funding for the National Center for Special Education Research (NCSER) who did not see an increase in FY 2016. NCSER's research informs evidence-based interventions and strategies to support the development and academic success of children with disabilities, which includes strategies for improving early childhood special education; advancing reading, writing, and language development; educating students with autism spectrum disorders; and helping students transition to post-secondary education and careers.

We support the proposed funding level for IDEA and urge you to maintain this amount without negatively impacting funding for other education programs. IDEA is the major—but not sole—vehicle for providing education to students with disabilities. In fact, students with disabilities are general education students first, with nearly two-thirds of students with disabilities spending at least 80 percent of their time in a general education setting.

APA encourages the subcommittee to make a significant investment in the newly reauthorized Student Support and Academic Enrichment Grants program (SSAEG), found in Title IV, Part A of the bipartisan Every Student Succeeds Act (ESSA). This program is a consolidation of over 20 federal programs that is intended to be more widely accessible to more students. It will now support: safe and healthy students activities, such as providing mental health services to students; increasing student access to STEM, computer science and accelerated learning courses, physical education, art, music, foreign languages and college and career counseling; funds for an effective school library program; and providing students with access to technology and digital materials and educators with technology professional development opportunities. Authorized at $1.65 billion, this formula grant program to States and LEAs, if appropriately funded, will make a significant difference in the academic achievements of all students. The funding level must be adequate to support a realistic and robust formula grant program as authorized in ESSA and APA urges the Committee to provide funding as close as possible to the authorized level. In addition, APA urges the Committee to strengthen the investment in other important elementary and secondary programs like Javits Gifted and Talented education.

APA supports increased funding for the Graduate Assistance in Areas of National Need (GAANN) program. GAANN supports fellowships to institutions of higher education for outstanding

students with financial need pursuing degrees in areas of national need, including psychology. Supporting our nation's graduate students is an investment worth making. APA urges the Committee not to shortchange this population of students and to support programs that make graduate study more affordable and accessible to students with financial need. Investments in graduate study are part of an effective strategy of ensuring our nation's future economic competitiveness as well as ensuring we have a highly trained workforce to meet the health care needs of the nation's population.

Indian Health Service

APA supports increased funding for the American Indians Into Psychology Program (In Psych). The In Psych program addresses the need for culturally competent psychologists in the American Indian community to help address extremely high rates of suicide and substance use. We ask that the program be funded at $1.5 million up from $715,078 as it has not kept up with the need.

Thank you again for the opportunity to submit this testimony for the record.

TESTIMONY ON BEHALF OF THE MARCH OF DIMES REGARDING FISCAL YEAR 2017 APPROPRIATIONS FOR THE DEPARTMENT OF HEALTH AND HUMAN SERVICES

Prepared for the Subcommittee on Labor, Health and Human Services, and Education, and Related Agencies

MARCH OF DIMES: FISCAL YEAR 2017 FEDERAL FUNDING PRIORITIES (dollars in thousands)

PROGRAM	FISCAL YEAR 2017 REQUEST
National Institutes of Health (total)	**34,500,000**
National Institute of Child Health and Development	1,441,000
National Human Genome Research Institute	558,000
National Institute on Minority Health and Disparities	302,000
National Institute of Environmental Health Sciences	732,200
National Children's Study Alternative	165,000
Centers for Disease Control and Prevention (total)	**7,800,000**
National Center for Birth Defects and Developmental Disabilities	143,068
Birth Defects Research and Surveillance	20,045
Folic Acid Campaign	3,323
Section 317 Immunization Program	650,000
Polio Eradication	174,000
Safe Motherhood Initiative	46,000
Preterm Birth	2,000
National Center for Health Statistics	170,000
Health Resources and Services Administration (total)	**7,480,000**
Title V Maternal and Child Health Block Grant	650,000
SPRANS- Infant Mortality and Preterm Birth	3,000
Heritable Disorders	18,000
Universal Newborn Hearing	18,660
Healthy Start	103,500
Children's Hospitals Graduate Medical Education	300,000
Agency for Healthcare Research and Quality (total)	**364,000**

Mr. Chairman and members of the subcommittee, I am Cindy Pellegrini, Senior Vice President of Public Policy and Government Affairs at the March of Dimes. I am testifying today to support robust funding for a number of programs throughout the Department of Health and Human Services (HHS) that promote maternal and child health.

The March of Dimes, a unique collaboration of scientists, clinicians, parents, members of the business community, and other volunteers representing every state, the District of Columbia and Puerto Rico, appreciates this opportunity to submit testimony for the record on fiscal year

2017 (FY17) appropriations for the Department of Health and Human Services (HHS). For over 75 years, the March of Dimes has promoted maternal and child health through activities such as funding research and field trials for the eradication of polio, promoting newborn screening, and educating medical professionals and the public about best practices for healthy pregnancy. Today, the March of Dimes works to improve the health of women, infants and children by preventing birth defects, premature birth, and infant mortality through research, community services, education, and advocacy. The March of Dimes recommends the following funding levels for programs and initiatives that are essential investments in maternal and child health.

Zika Virus

Our nation faces an unprecedented challenge in the form of a mosquito-borne virus that causes devastating birth defects. It is imperative that Congress provide resources immediately to address the full span of activities necessary to track, treat, and ultimately prevent Zika infections. This includes a wide range of activities throughout HHS agencies, including vaccine research at the National Institutes of Health (NIH), vector control, diagnostic testing, public education, and birth defects surveillance at the Centers for Disease Control and Prevention (CDC), and much more. Only a robust, multi-faceted response will prevent the virus from gaining a foothold in the United States. The March of Dimes calls upon the Committee to do everything in its power to protect pregnant women and their infants from this deadly virus.

***Eunice Kennedy Shriver* National Institute of Child Health and Human Development**

The March of Dimes recommends at least $34.5 billion for NIH and $1.441 billion for the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD) in FY17. This funding will allow NICHD to sustain vital research on preterm birth and related issues through extramural grants, Maternal-Fetal Medicine Units, the Neonatal Research Network and the intramural research program. This funding would also allow NICHD to continue investments in transdisciplinary research to identify the causes of preterm birth, as recommended in the Director's 2012 Scientific Vision for the next decade, the Institute of Medicine 2006 report on preterm birth, and the 2008 Surgeon General's Conference on the Prevention of Preterm Birth. The March of Dimes fully supports NICHD's pursuit of transdisciplinary science, which facilitates the exchange of scientific ideas and leads to novel approaches to understanding complex health issues – and how to treat or prevent them. NIH's work in transdisciplinary research is complemented by the March of Dimes commitment to invest $75 million over ten years in transdisciplinary research to unravel the causes of preterm birth.

Title V Maternal and Child Health Block Grant Program

The March of Dimes recommends funding the Title V Maternal and Child Health Block Grant Program at $650 million. More than half of pregnant women and more than a third of infants and children benefit from maternal and child health block grant programs.

The March of Dimes also recommends Congress specify that $3 million within the Title V Special Projects of Regional and National Significance account be used to support current preterm birth and infant mortality initiatives, as authorized in the PREEMIE Act, and to support the expansion of its initiatives nationwide. The PREEMIE Reauthorization Act renewed preterm birth-related

demonstration projects, which are aimed at improving education, treatment and outcomes for babies born preterm. This funding will support the Collaborative Improvement & Innovation Network (CoIIN) to Reduce Infant Mortality, which assists states focusing on a range of interventions proven to reduce preterm birth and improve maternal and child health.

Safe Motherhood Initiative

Preterm birth is a serious health problem that costs the United States more than $26 billion annually. Alarmingly, one in 10 infants in the United States is born preterm. Prematurity is the leading cause of neonatal mortality and the second leading cause of infant mortality.

In 2013, Congress passed the PREEMIE Reauthorization Act (P.L. 113-55), which renews our nation's commitment to giving every baby a healthy start. The mission of the Safe Motherhood Initiative at the Centers for Disease Control and Prevention's (CDC) National Center for Chronic Disease Prevention and Health Promotion is to promote optimal reproductive and infant health. The March of Dimes recommends funding of $46 million for the Safe Motherhood program and strongly urges maintenance of the preterm birth sub-line at $2 million, as reauthorized in the PREEMIE Reauthorization Act, to retain and buttress current preterm birth research within the CDC.

National Center on Birth Defects and Developmental Disabilities

According to the CDC, an estimated 120,000 infants in the United States are born with major structural birth defects each year. While birth defects are a leading cause of infant mortality, the causes of more than 70 percent of birth defects remain unknown. Federal investments are sorely needed to support research to discover the causes of all birth defects, and for the development of effective interventions to prevent them or reduce their prevalence.

The National Center on Birth Defects and Developmental Disabilities (NCBDDD) is the lead federal agency tasked with supporting vital surveillance, research, and prevention activities aimed at birth defects and developmental disabilities. Given the center's expertise, NCBDDD staff are playing a vital role in the international and domestic response to the Zika virus. Currently, about 12 percent of the NCBDDD's staff are deployed to the CDC's Emergency Operations Center, while many other staff are providing technical assistance while maintaining ongoing NCBDDD activities.

For FY17, the March of Dimes recommends funding of $143.068 million for the NCBDDD. We also request at least $20.045 million to support birth defects research and surveillance, and $3.323 million to support folic acid education.

Birth defects research and surveillance activities have been severely curtailed due to funding cuts, slowing the pace of research identifying the causes of birth defects, and decreasing the ability to track birth defects. Specifically, budgetary constraints have led to the elimination of two Centers for Birth Defects Research and Prevention. Expertise from the previously funded Centers in Texas and Utah (including knowledge regarding medications used during pregnancy, environmental exposures of concern, maternal infections, and birth defects risk among

Hispanics) is no longer contributing to the study, and 25 percent fewer families are participating in CDC birth defects research. Birth defects surveillance programs funded by NCBDDD have gone from 28 in 2004 to 14 in 2016, with a 40 percent (800,000) reduction in the number of live births monitored by states. This reduction in surveillance, study, and scope will mean fewer treatments, fewer reductions in birth defects, and ultimately higher health care costs for families and the government. These cuts also have major implications for our nation's ability to track birth defects caused by the Zika virus. We urge Congress in the strongest terms to bolster funding for NCBDDD, and particularly for birth defects surveillance.

Immunization Programs

The March of Dimes is also committed to ensuring that mothers and children are protected from vaccine-preventable diseases, and strongly urges the committee to reject proposed cuts to the Section 317 Immunization program included in the President's FY17 budget. The March of Dimes recommends funding of $650 million for the Section 317 Immunization program and $174 million for the continuing effort to eradicate polio worldwide.

Newborn Screening

Newborn screening detects conditions in newborns that, if left untreated, can cause disability, developmental delays, intellectual disabilities, serious illnesses, or even death. If diagnosed early, many of these disorders can be managed successfully. The March of Dimes urges funding of $18 million for the Health Resources and Services Administration's heritable disorders program, which plays a critical role in assisting states in the adoption of additional screenings, educating providers and consumers, and ensuring coordinated follow-up care.

Also funded by this program is 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). This year, the ACHDNC added two new conditions to the RUSP, bring the total number of recommended screens to 34. Additional funding for 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.

Conclusion

March of Dimes volunteers and staff representing every state, the District of Columbia and Puerto Rico look forward to working with appropriators and all of Congress to secure the resources needed to improve the health of the nation's mothers, infants and children.

NEPHCURE
Kidney International

Saving Kidneys • Saving Lives

BOARD OF DIRECTORS
Irv Smokler, Ph.D. – *President*
Ron Cohen - *Vice President*
Michael Levine – *Vice President*
Carol Smokler, Ph.D. – *Secretary*
Andrew Silverman – *Treasurer*
Elaine Kamil, M.D.
Co-Medical Director
David Kershaw, M.D.
Co-Medical Director
William Smoyer, M.D.
Co-Medical Director

Kathleen Broderick
Claire Cascio, R.N.
Jim Duquette
Richard Foster
Jennifer Geisser
Scott Goldstein
Sarretta McDonough, Esq.
John Roy
Joshua Roy
Sondra Stubblefield
Charles Turner
Manu Varma

Mark Stone
Chief Executive Officer

SCIENTIFIC ADVISORY BOARD
Lawrence B. Holzman, M.D.
Chairman
University of Pennsylvania
Gerald Appel, M.D.
Columbia University
Ross Cagan, Ph.D.
Mount Sinai School of Medicine
Daniel Cattran, M.D.
University of Toronto
Marilyn Gist Farquhar, Ph.D.
University of California (San Diego)
Friedhelm Hildebrandt, M.D.
University of Michigan
Frederick Kaskel, M.D., Ph.D.
Albert Einstein College of Medicine
Peter Mundel, M.D.
Harvard University
Martin R. Pollak, M.D.
Harvard University
Jochen Reiser, M.D., Ph.D.
Rush University Medical Center
Andrey S. Shaw, M.D.
Washington University (St. Louis)
Karl Tryggvason, M.D., Ph.D.
Karolinska Institutet (Stockholm)
Roger Wiggins, M.D.
University of Michigan

POSTHUMOUS EMERITUS
Michelle Winn, M.D.
Duke University

WASHINGTON REPRESENTATIVE

STATEMENT OF
IRVING SMOKLER, PH.D.
PRESIDENT AND FOUNDER
NEPHCURE KIDNEY INTERNATIONAL

ON BEHALF OF
NEPHCURE KIDNEY INTERNATIONAL

FISCAL YEAR 2017 APPROPRIATIONS FOR THE NATIONAL INSTITUTES OF HEALTH

SUBMITTED TO THE
HOUSE COMMITTEE ON APPROPRIATIONS
SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES, EDUCATION, AND RELATED AGENCIES

APRIL 15, 2016

SUMMARY OF RECOMMENDATIONS FOR FY17:

1) PROVIDE $34.5 BILLION FOR THE NATIONAL INSTITUTES OF HEALTH (NIH)

2) PROVIDE A CORRESPONDING INCREASE TO THE NIH INSTITUTES AND CENTERS

3) SUPPORT THE EXPANSION OF THE FSGS/NS RESEARCH PORTFOLIO AT NIDDK, THE OFFICE OF RARE DISEASES RESEARCH (ORDR) AND THE NATIONAL INSTITUTE ON MINORITY HEALTH AND HEALTH DISPARITIES (NIMHD) BY FUNDING MORE RESEARCH PROPOSALS FOR PRIMARY GLOMERULAR DISEASE

Thank you for the opportunity to present the views of NephCure Kidney International regarding research on idiopathic focal segmental glomerulosclerosis (FSGS) and primary nephrotic syndrome (NS). NephCure

is the only non-profit organization exclusively devoted to fighting FSGS and the NS disease group. Driven by a panel of respected medical experts and a dedicated band of patients and families, NephCure works tirelessly to support kidney disease research and awareness.

NS is a collection of signs and symptoms caused by diseases that attack the kidney's filtering system. These diseases include FSGS, Minimal Change Disease and Membranous Nephropathy. When affected, the kidney filters leak protein from the blood into the urine and often cause kidney failure, which requires dialysis or kidney transplantation. According to a Harvard University report, 73,000 people in the United States have lost their kidneys as a result of FSGS. Unfortunately, the causes of FSGS and other filter diseases are poorly understood.

FSGS is the second leading cause of NS and is especially difficult to treat. There is no known cure for FSGS and current treatments are difficult for patients to endure. These treatments include the use of steroids and other dangerous substances which lower the immune system and contribute to severe bacterial infections, high blood pressure and other problems in patients, particularly child patients. In addition, children with NS often experience growth retardation and heart disease. Finally, NS that is caused by FSGS, MCD or MN is idiopathic and can often reoccur, even after a kidney transplant.

FSGS disproportionately affects minority populations and is five times more prevalent in the African American community. In a groundbreaking study funded by NIH, researchers found that FSGS is associated with two APOL1 gene variants. These variants developed as an evolutionary response to African sleeping sickness and are common in the African American patient population with FSGS/NS. Researchers continue to study the pathogenesis of these variants.

FSGS has a large social impact in the United States. FSGS leads to end-stage renal disease (ESRD) which is one of the most costly chronic diseases to manage. In 2008, the Medicare program alone spent $26.8 billion, 7.9% of its entire budget, on ESRD. In 2005, FSGS accounted for 12% 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 health care costs and reduce health status disparities. For this reason, and on behalf of the thousands of families that are significantly affected by this disease, we encourage support for expanding the research portfolio on FSGS/NS at the NIH.

ENCOURAGE FSGS/NS RESEARCH AT NIH

There is no known cause or cure for FSGS and scientists tell us that much more research needs to be done on the basic science behind FSGS/NS. More research could lead to fewer patients undergoing ESRD and tremendous savings in health care costs in the United States. NephCure works closely with NIH and has partnered with NIH on two large studies that will advance the pace of clinical research and support precision medicine. These studies are the Nephrotic Syndrome Study Network and the Cure Glomerulonephropathy Network.

With collaboration from other Institutes and Centers, ORDR established the *Rare Disease Clinical Research Network*. This network provided an opportunity for NephCure Kidney International, the University of Michigan, and other university research health centers to come together to form the Nephrotic Syndrome Study Network (NEPTUNE). Now in its second 5-year funding cycle, NEPTUNE has recruited over 450 NS research participants, and has supported pilot and ancillary studies utilizing the NEPTUNE data resources. **NephCure urges the**

subcommittee to continue its support for RDCRN and NEPTUNE, which has tremendous potential to facilitate advancements in NS and FSGS research.

NIDDK recently initiated the Cure Glomerulonephropathy Network (Cure GN), a multicenter 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 encourage NIDDK to continue to support CureGN as well as other primary glomerular disease program announcements.**

It is estimated that annually there are 20 new cases of ESRD per million African Americans due to FSGS, and 5 new cases per million Caucasians. This disparity is largely due to variants of the APOL1 gene. Unfortunately, the incidence of FSGS is rising and there are no known strategies to prevent or treat kidney disease in individuals with the APOL1 genotype. NIMHD began supporting research on the APOL1 gene in FY13. Due to the disproportionate burden of FSGS on minority populations, it remains appropriate for NIMHD to continue to advance this research. **NephCure asks the subcommittee to encourage NIMHD to continue to study FSGS/NS, including the APOL1 gene.**

Thank you for the opportunity to present the views of the FSGS/NS community. Please contact NephCure Kidney International if additional information is required.

National Energy Assistance Directors' Association, Prepared for the Subcommittee on Labor, Health and Human Services and Education and Related Agencies. Addressed to the US Department of Health and Human Services, Administration for Children and Families

The members of National Energy Assistance Directors' Association (NEADA), representing the state directors of the Low Income Home Energy Assistance Program (LIHEAP) would like to first take this opportunity to thank the members of the Subcommittee for considering our funding request for FY 2017. For FY 2017 we are requesting the Committee restore program funding to the FY 2011 level of $4.7 billion.

The funding request would allow states to increase program services to the level provided in FY 2011 and allow us to increase the number of households served from 6.7 million to 8 million and the percentage of households served from about 19 percent in FY 2016 to about 22 percent and fund about 50 percent of the cost of home heating for eligible households.

In addition, the lack of a final program appropriation prior to the beginning of the fiscal year creates significant administrative problems for states in setting their program eligibility guidelines. We are concerned that states will be hampered in their ability to administer their programs efficiently due to the lack of advanced funding. In order to address this concern, we are requesting advance appropriations of $4.7 billion for FY 2018.

LIHEAP is the primary source of heating and cooling assistance for some of the poorest families in the United States. In FY 2016, the number of households receiving heating assistance is expected to remain at about 6.7 million or about 19 percent of eligible households, with an average grant size of about $425. In addition, the program is expected to reach about 1 million households for cooling assistance, the same level that received assistance in FY 2015.

Program funding for LIHEAP has been significantly cut from $5.1 billion in FY 2010 to the current level of $3.3 billion. As a result, states have had to reduce the number of households receiving assistance by 1.3 million, from 8 million to the current level of 6.7 million. Program cuts have hurt the ability of states to help the nation's poorest households pay their energy bills. The average grant has further been reduced from $520 in FY 2010 to the current level of about $425.

At the same time, LIHEAP is in a period of transition. Along with the Administration for Children and Families, the Department that oversees the program, LIHEAP offices are working to enhance current program integrity measures including developing modernized web-based intake systems, and instituting external verification of applicant-submitted data. In addition, they are developing nationwide performance measures that will give Congress and the public a clear picture of the effectiveness of LIHEAP in helping low income households. NEADA believes these efforts will lead to a more responsive and more cost-effective program.

LIHEAP in the President's Budget

The Obama Administration released its fiscal year 2017 (FY17) budget on February 9, 2016. This budget would reduce core block grant funding for LIHEAP from $3.39 billion to $3.0

billion. This represents a cut of $390 million or about 12%. The budget did not provide a rationale for the cut. We urge the Committee to reject this proposal.

Weatherization. Current law allows states to set aside up to 15 percent of their allocation for Weatherization and up to 25 percent with a waiver. The Administration's proposal would allow states to set-aside up to 40 percent without a waiver. We are recommending that the Committee reject this proposal. The current law provides states with sufficient flexibility to design their weatherization programs in context of other resource that might be available for this purpose, allowing states to strike the proper balance between bill payment assistance and efficiency. In addition, we believe that increasing the ceiling for Weatherization within the block grant would undermine the primary purpose of LIHEAP which is to help poor families pay their home energy bills.

One aspect of the budget is potentially very positive for LIHEAP. It would add a new contingency fund of $560 million. We urge the Committee to consider this proposal assuming it would not detract from providing full funding for the base program.

What is the Impact of Declining Federal Funds?

Surveys of families receiving federal assistance have been consistent over the years. Poor families struggle to pay their home energy bills. When they fall behind, they risk shut-off of energy services or they are not able to afford the purchase of delivered fuels. In FY 2011, NEADA conducted a survey of approximately 1,800 households that received LIHEAP benefits.

The results show that LIHEAP households are among the most vulnerable in the country.

- 40 percent have someone age 60 or older
- 72 percent have a family member with a serious medical condition
- 26 percent use medical equipment that requires electricity
- 37 percent went without medical or dental care
- 34 percent did not fill a prescription
- 85 percent of people with a medical condition are seniors

LIHEAP's impact in many cases goes beyond providing bill payment assistance by playing a crucial role in maintaining family stability. It enables elderly citizens to live independently and ensures that young children have safe, warm homes to live in.

Energy Prices and their Impact on Low Income Households

While energy prices have stabilized in some cases declined from previous year highs they remain unaffordable for millions of low income households. According to the US Energy Information Administration, the cost of home heating this winter with natural gas was $525, electricity $903, heating oil, $1,033, propane $1,696 in the Northeast and $1,015 in the Midwest. EIA also reported that the average summer electricity expenditures is expected to remain at an unaffordable $407, about the same as last year.

Energy prices fall hardest on lower income households. In FY 2014, mean burden for low-income was 10% almost four times the rate for non-low income households (2.4%). Of even

greater concern about one-third of lower income households have energy burden greater than 15% of income and one in six have an energy burden greater than 25% of income.
Source: FY 2014 Home Energy Notebook, Administration for Children and Families.

Faces of LIHEAP

Alabama: A single mother in Alabama supporting three children on minimum wage was often forced to decide whether to pay utility bills or rent. She received LIHEAP to help pay her bill and was enrolled in an energy education class to help manage her energy usage. In addition to the LIHEAP benefit, she was able to bring down her energy bill from about $570 a month to $495 month, a savings of $75, as a result of the class.

California: A young mother of three lived in an older all-electric home and had their electricity shut off due to a past-due bill of about $800. She worked full time making minimum wage and her husband worked as a seasonal laborer. With no electricity, the family could not heat their home, access hot water, or operate appliances. LIHEAP was able to assist the family by paying their past due bill to get the electricity turned back on. She was also referred to the County's Weatherization Program, which assists families in making their homes more energy efficient.

Connecticut: A single mother of two facing the challenges of being homeless came to the state for help. Through Connecticut's connected services, she received a housing subsidy, $505 in LIHEAP funds, and was enrolled in the utility company's Matching Payment Program.

Georgia: A 77 year-old disabled senior living on SSI was facing shut-off due to unaffordable winter energy bills. During the winter months every year her heating bills peaked as the result of having to maintain a consistence home heating temperature due to her disability and other illnesses. Her gas bill was in danger of disconnection with a balance of $612 and an additional past due portion of $355. With the senior meeting the eligibility requirement for both the LIHEAP maximum benefit $350 and Home Energy Assistance Team (H.E.A.T) program funds of $350 the program was able to successfully assist this senior to bring her home heating bill current which resulted in the senior maintaining home heating throughout the remainder of winter.

While visiting the home of a senior citizen to take a LIHEAP application, the Program Coordinator noticed the oven and top burners of her stove were on, as well as that she was wearing a heavy over wrap. During the intake process it was discovered that her home heating furnace was not working. Based on the her income she received the maximum LIHEAP benefit of $350 and was referred to the Weatherization Assistance Program (WAP) to have her heating season evaluated. The Weatherization Program Coordinator came out and confirmed that the furnace needed to be replaced. A WAP team was dispatched to the senior home to install a new furnace, the senior could immediately feel the difference in the heating of the home and was extremely grateful.

Idaho: A 90 year-old woman in rural Idaho was referred by LIHEAP to Weatherization after she indicated that she had a broken furnace. Weatherization staff found that she was using a coffee can to carry wood pellets from an outdoor shed to a pellet stove in her living room, because she was not able to carry an entire bag. With no other backup heat source, she would have to leave

her home if the unreliable stove broke. Because of the referral from LIHEAP, the Weatherization program was able to install a new high efficiency furnace and weatherize her home. This saved her money on her monthly heating bill and allowed her to stay in her home.

Illinois: A single man who had been living in a tent was able to afford an apartment for the first time in years when he discovered he had an old bill with the utility and would not be able to get utilities in his new home. LIHEAP was able to get him connected and help him get up-to-date on his bills.

Oklahoma: A young single woman with medical issues was working part time as a cashier and taking care of her elderly grandmother. She was able to use LIHEAP to maintain service while she was between jobs, preventing her and her mother from entering a shelter. She was also able to use LIHEAP emergency assistance to prevent disconnect of her electricity when her new salary was not enough to cover the bill.

Pennsylvania: A disabled cancer patient lost her home through foreclosure but was still in the residence pending eviction. Her furnace was shut down for safety reasons after the state weatherization team discovered it was leaking carbon monoxide. The property was acquired by an out-of-state corporation that refused to allow the weatherization team to repair the furnace. The state LIHEAP office was able to use LIHEAP weatherization funds to provide space heaters for the woman until she was able to make other living arrangements, saving her from making the choice of living in a house made hazardous from carbon monoxide or in freezing temperatures.

Tennessee: A woman who is bed ridden and paralyzed from the waist down had to cut back on other necessities to pay her medical bills. At the beginning of last winter, she saved energy by only turning on the lights when her nurse came to visit. She also kept her thermostat on 60 degrees and asked her nurse to layer her clothing and put extra blankets on her before she left. Since receiving LIHEAP, she has been able to leave a light on at night to make her feel more secure and to keep the home a comfortable temperature.

Wyoming: An elderly woman was facing eviction because she got behind on her utility bills. She was having trouble stretching her social security check to cover her utilities, her cancer treatments, and the cost of travel to receive treatment. LIHEAP helped her out with her bill, ensuring she could stay in her home. "We might not be able to eat very well or pay for medicines, but at least we can be warm in our own homes with the help of LIHEAP".

DYSTONIA
MEDICAL
RESEARCH
FOUNDATION

serving all dystonia-affected persons

Lifetime Honorary Directors
Stanley Fahn, MD
Martin B. Sloate

Board of Directors
Samuel Belzberg
Chairman of the Board/Co-founder
Art Kessler
President
Dennis Kessler
Vice President of Development
Rosalie Lewis
Vice President of Public Policy
Barbara Kessler
Vice President of Awareness & Activities
Deborah Kilpatrick, PhD
Vice President of Science
Karen K. Ross, PhD
Vice President of Support
Mark Rudolph,
Treasurer
Sandra Weil
Network Liaison

Directors
Frances Belzberg, *Co-founder*
Donna Driscoll
Nancy Harris
Marilynne Herbert
Richard A. Lewis, MD
Diane Rudolph
John Symonds
Mahlon R. DeLong, MD
Scientific Director, ex officio
Janet Hieshetter
Executive Director, ex officio
Billy McLaughlin
ex officio
Paula Schneider
Leadership Chairperson, ex officio

Medical and Scientific Advisory Council
Mahlon R. DeLong, MD
Scientific Director
Allison Brashear, MD
Susan Bressman, MD
Jonathan Brotchie, PhD
Robert Chen, MA, MBBChir, MSc, FRCPC
Marc Diamond, MD
Bogdan Draganski, MD
Thomas Gasser, MD
Gregg Gundersen, PhD
Phyllis Hanson, MD, PhD
Kamran Khodakhah, PhD
Jonathan Mink, MD, PhD
Joel Perlmutter, MD
Antonio Pisani, MD
Rachel Saunders-Pullman, MD, MPH
Jerrold Vitek, MD, PhD
Michal Zolkiewski, PhD
Cynthia Comella, MD, *ex officio*
Ted Dawson, MD, PhD, *ex officio*
H.A. Jinnah, MD, PhD, *ex officio*

One East Wacker Drive • Suite 2810
Chicago, IL 60601-1905
P (312) 755-0198 F (312) 803-0138
www.dystonia-foundation.org
dystonia@dystonia-foundation.org

STATEMENT OF
Janet Hieshetter
Executive Director
Dystonia Medical Research Foundation

REGARDING
Fiscal Year 2017 Appropriations for the National Institutes of Health

SUBMITTED TO
Senate Committee on Appropriations
Subcommittee on Labor, Health and Human Services, Education, and Related Agencies

April 15, 2016

SUMMARY OF RECOMMENDATIONS FOR FISCAL YEAR 2017:

- **Provide $34.5 billion for the National Institutes of Health (NIH) and proportional increases across its Institutes and Centers**
- **Continue to support natural history studies on dystonia, like the *Dystonia Coalition* within the Rare Disease Clinical Research Network (RDCRN) coordinated by the Office of Rare Diseases Research (ORDR) in the National Center for Advancing Translational Sciences (NCATS)**
- **Expand dystonia research supported by NIH through the National Institute on Neurological Disorders and Stroke (NINDS), the National Institute on Deafness and other Communication Disorders (NIDCD), the National Eye Institute (NEI), and NCATS**

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 (NIH)

The DAN urges the Subcommittee to continue its support for natural history studies on dystonia that will advance the pace of clinical and translational research to find better treatments and a cure. In addition, Congress should support NINDS, NCATS, 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), the National Eye Institute (NEI), and the Office of Rare Diseases Research (ORDR) within the National Center for Advancing Translational Sciences (NCATS).

ORDR coordinates the Rare Disease Clinical Research Network (RDCRN) which provides support for studies on the natural history, epidemiology, diagnosis, and treatment of rare diseases. RDCRN includes the *Dystonia Coalition*, a partnership between researchers, patients, and patient advocacy groups to advance the pace of clinical research on cervical dystonia, blepharospasm, spasmodic dysphonia, craniofacial dystonia, and limb dystonia. The *Dystonia Coalition* has made tremendous progress in preparing the patient community for clinical trials as well as funding promising studies that hold great hope for advancing our understanding and capacity to treat primary focal dystonias. Studies like the *Coalition* remain a priority for the community and Congress should continue to support these initiatives.

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.

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.

In summary, the DMRF recommends the following for fiscal year 2017:

- Provide $34.5 billion for NIH and a proportional increase for its Institutes and Centers

- Support natural history studies on dystonia like the *Dystonia Coalition*, part of the Rare Diseases Clinical Research Network coordinated by ORDR within NCATS
- Expand the dystonia research portfolio at NIH through NINDS, NIDCD, NEI, and NCATS

DMRF was founded in 1976. Since its inception, the goals of DMRF have remained to advance research for more effective treatments of dystonia and ultimately find a cure; to promote awareness and education; and support the needs and well being of affected individuals and their families.

Thank you for the opportunity to present the views of the dystonia community, we look forward to providing any additional information.

369 Highland Street
West Haven, CT 06516

Voice: 203-934-7077
Fax: 203-934-7078

www.CDR-CT.org

36 Killingworth Turnpike
Clinton, CT 06413

Voice: 860-664-5057
Fax: 860-664-5157

www.Wheel-A-Thon.org

House Committee on Appropriations
Subcommittee on Labor, Health, and Human Services

Testimony on FY 2017 Appropriation for ACL - Centers for Independent Living

Name: Marc Anthony Gallucci

Title: Executive Director

Institutional Affiliation: Center for Disability Rights - Connecticut

I am writing to support the National Council on Independent Living's request for Congress to reaffirm your commitment to the more than 57 million Americans disabilities by increasing funding in the HHS appropriations for Centers for Independent Living (CILs). I am asking that you increase funding by $200 million, for a total of $301 million for the Independent Living line item in FY 2017.

Our CIL, Center for Disability Rights serves Connecticut's 3rd Congressional District and parts of the 2nd and 4th. In the last year, we have served over 4,000 people with disabilities and their families, transitioned 63 persons out of nursing homes and into the community, and provided

over 200 hours of training and technical assistance to businesses, municipalities, and non-profits on how to be more accessible to people with disabilities.

CILs are cross-disability, non-residential, community-based, nonprofit organizations that are designed and operated by individuals with disabilities. CILs are unique in that they are directly governed and staffed by people with all types of disabilities, including people with mental, physical, sensory, cognitive, and developmental disabilities. Each of the 365 federally funded centers provides five core services: information and referral, individual and systems advocacy, peer support, independent living skills training, and transition services, which were added with the passage of the Workforce Innovation and Opportunity Act (WIOA). From 2012-2014, CILs provided the core services to nearly 5 million people with disabilities, and provided additional services such as housing assistance, transportation, personal care attendants, and employment services to hundreds of thousands of individuals. During this same period, prior to transition being added as a core service, CILs transitioned 13,030 people with disabilities from nursing homes and other institutions into the community.

Transition services were added as a fifth core service with the 2014 reauthorization of the Rehabilitation Act within the Workforce Innovation and Opportunity Act. Transition services include the transition of individuals with significant disabilities from nursing homes and other institutions to home and community-based residences with appropriate supports and services, assistance to individuals with significant disabilities at risk of entering institutions to remain in

the community, and the transition of youth with significant disabilities to postsecondary life. This core service is vital to achieving full participation for people with disabilities.

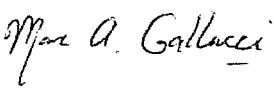
Every day, CILs are fighting to ensure that people with disabilities gain and maintain control over our own lives. We know that this cannot occur when people reside in institutional settings. Opponents of deinstitutionalization say that allowing people with disabilities to live in the community will result in harm. We know that the 13,030 people with disabilities who CILs successfully transitioned out of nursing homes and institutions from 2012-2014 prove otherwise. Additionally, when services are delivered in an individual's home, the result is a tremendous cost savings to Medicaid, Medicare, and states. Community-based services enable people with disabilities to become less reliant on long-term government supports, and they are significantly less expensive than nursing home placements. We are grateful that Congress demonstrated their understanding and support for community-based services when WIOA was passed and transition was added as a fifth core service.

Since transition services were added as a core service, the need for funding is critical. Moreover, CILs need additional funding to restore the devastating cuts to the Independent Living program, make up for inflation costs, and address the increased demand for independent living services. In 2016, the Independent Living Program is receiving $2.5 million less in funding than it was in 2010. It is simply not possible to meet the increasing demand for services and effectively provide transition services without additional funding. Increased funding should be reinvested from the

billions currently spent to keep people with disabilities in costly Medicaid nursing homes and institutions and out of mainstream society.

Centers for Independent Living play a crucial role in the lives of people with disabilities, and work tirelessly to ensure that people with disabilities have a real choice in where and how they live, work, and participate in the community. Additionally, CILs are an excellent service and a bargain for America, keeping people engaged with their communities and saving taxpayer money. NCIL is dedicated to increasing the availability of the invaluable and extremely cost-effective services CILs provide, and they have submitted written testimony with a similar request. I strongly support NCIL's testimony.

Respectfully Submitted:



Marc Anthony Gallucci, Esq.

Center for Disability Rights - CT

The National Campaign
to Prevent Teen and Unplanned Pregnancy

April 15, 2016

United States House of Representatives
Committee on Appropriations
Subcommittee on Labor, Health and Human Services,
Education, and Related Agencies
The Capitol H-305
Washington, DC 20515

RE: FY 2017 Written Testimony For The Record

Dear Chairman Cole, Ranking Member DeLauro, and members of the Subcommittee:

Thank you for the opportunity to submit written testimony for the record in the FY 2017 appropriations process. My name is Rachel Fey, Director of Public Policy at The National Campaign to Prevent Teen and Unplanned Pregnancy, a research-based, nonpartisan, nonprofit organization founded in 1996. Our mission is to improve the lives and future prospects of children and families and, in particular, to help ensure that children are born into stable families who are committed to and ready for the demanding task of raising the next generation. Our strategy is to prevent teen pregnancy and unplanned pregnancy, especially among single, young adults. Ensuring that young people have access to high quality, evidence-based teen pregnancy prevention education is one critical element in helping more young people delay pregnancy and parenting. To that end, we respectfully recommend restoring funding to the Office of Adolescent Health (OAH)'s evidence-based Teen Pregnancy Prevention Program (TPPP) to $110 million, the level it was initially funded at in FY 2010. Currently the program is funded at $101 million for FY 2016.

Since the early 1990s, teen pregnancy and birth rates have declined by 55 percent and 61 percent, respectively.[1,2] However, it is still the case that roughly one in four girls in this country will become pregnant before the age of 20, and nearly half of all teen girls in foster care have been pregnant at least once by the age of 19. Even with dramatic across the board declines, inequalities persist for some racial and ethnic groups. Four in 10 African American girls and one in three Latinas will become pregnant before age 20, compared to roughly one in six non-Hispanic White teen girls.[3] Moreover, the United States has much higher teen pregnancy rates than our trading partners.

In addition to costing taxpayers more than $9.4 million annually, our high teen pregnancy rates threaten to hinder our nation's progress, as young parents have less opportunity to get the education and skills they need to compete in a 21st century workforce.[4] For instance, 30 percent of teen girls who have dropped out of high school cite pregnancy/parenthood as a key reason. And fewer than two percent of those who have a child before age 18 attain a college degree by

age 30. However, the unprecedented declines over the past two decades show that progress is possible.[5] Since TPPP and one other federal funding stream for evidence-based teen pregnancy prevention programs began in 2010, the teen birth rate in the U.S. has declined 29%, a drop about twice as large as in any other four-year period.[6]

TPPP supports 81 competitive grants to a broad range of organizations and agencies in 38 states and the Marshall Islands. These five-year grants were awarded in FY 2015 and contingent on continued appropriations. The grants are expected to serve 1.2 million teens over the five-year period, focusing intensely on communities with the highest teen birth rates and the most at-risk youth.

TPPP is a pioneering example of evidence-based policymaking and represents an important contribution to building a body of evidence of what works to prevent teen pregnancy. This includes high quality implementation, evaluation, innovation, and learning from results. The program invests in two primary areas: replicating program models that have already been shown through careful evaluation to change teen behavior (Tier 1), and investing in research and demonstration projects to develop, replicate, refine, and test additional models and innovative strategies to prevent teen pregnancy (Tier 2). Three-quarters of the funding for TPPP is dedicated to Tier 1, while one-quarter is dedicated to Tier 2.

All Tier 1 models must meet well recognized high standards of evidence. That is, they must have been evaluated using a randomized controlled trial or quasi-experimental design. These evaluations must demonstrate actual changes in behavior (not just knowledge or behavioral intent), and results must be published in a peer-reviewed journal. With more than 30 models on the OAH's list of evidence-based programs, including abstinence-only programs, youth development programs, and those that address both abstinence and contraception, communities with Tier 1 grants have the flexibility to choose an approach that reflects their needs and values. For example, what people in New York City choose may be different from what people in Missouri choose—this is exactly what the current TPPP funding permits.

TPPP has invested heavily in the highest standards of evaluation and learning, as well as in innovation. This ensures that the menu of effective approaches to reducing teen pregnancy will continue to grow and be refined.

TPPP is one of the few government programs that both uses evidence as criteria for funding decisions and continues to rigorously evaluate its efforts and results. In fact, only about $1 out of every $100 spent on federal programs is backed by any evidence that the money is being spent wisely. At a time when leading experts—from The Brookings Institution to The Heritage Foundation to Results for America—and members of Congress are wisely and increasingly focused on ensuring that federally funded programs achieve results, and that they are rigorously evaluated in order to be sure that they do, TPPP is a smart use of taxpayer money.

TPPP also enjoys strong bipartisan public support.[7,8] It is supported by 83% of adults overall, including:

TESTIMONY OF
Lisa Butler
Executive Director

ON BEHALF OF
GBS|CIDP Foundation International
The Holly Building
104 1/2 Forrest Avenue Narberth, PA 19072

REGARDING
Fiscal Year 2017 (FY17) appropriations for medical research and public health programs funded annually through the Labor, Health and Human Services, Education, and Related Agencies (L-HHS) Appropriations Bill

SUBMITTED TO
The House Committee on Appropriations
Subcommittee on Labor, Health and Human Services, Education, and Related Agencies

ON
The 15th Day of April, 2016

THE FOUNDATION'S FY17 L-HHS APPROPRIATIONS RECOMMENDATIONS

- **At least $34.5 billion in program level funding for the National Institutes of Health (NIH).**
  - Proportional funding increases for NIH's National Institute of Neurological Disorders and Stroke (NINDS), National Institute of Allergy and Infectious Diseases (NIAID), and National Center for Advancing Translational Sciences (NCATS).

Chairman Cole 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 FY17 L-HHS Appropriations Bill.

ABOUT GBS, CIDP, VARIANTS AND RELATED CONDITIONS

Guillain-Barré Syndrome
GBS is an inflammatory disorder of the peripheral nerves outside the brain and spinal cord.

It's also known as Acute Inflammatory Demyelinating Polyneuropathy and Landry's Ascending Paralysis.

The cause of GBS is unknown. We do know that about 50% of cases occur shortly after a microbial infection (viral or bacterial), some as simple and common as the flu or food poisoning. Some theories suggest an autoimmune trigger, in which the patient's defense system of antibodies and white blood cells are called into action against the body, damaging myelin (nerve covering or insulation), leading to numbness and weakness.

GBS in its early stages is unpredictable, so except in very mild cases, most newly diagnosed patients are hospitalized. Usually, a new case of GBS is admitted to ICU (Intensive Care) to monitor breathing and other body functions until the disease is stabilized. Plasma exchange (a blood "cleansing" procedure) and high dose intravenous immune globulins are often helpful to shorten the course of GBS. The acute phase of GBS typically varies in length from a few days to months, with over 90% of patients moving into the rehabilitative phase within four weeks. Patient care involves the coordinated efforts of a team such as a neurologist, physiatrist (rehabilitation physician), internist, family physician, physical therapist, occupational therapist, social worker, nurse, and psychologist or psychiatrist. Some patients require speech therapy if speech muscles have been affected.

Recovery may occur over six months to two years or longer. A particularly frustrating consequence of GBS is long-term recurrences of fatigue and/or exhaustion as well as abnormal sensations including pain and muscle aches. These can be aggravated by 'normal' activity and can be alleviated by pacing activity and rest.

Chronic Inflammatory Demyelinating Polyneuropathy
CIDP is a rare disorder of the peripheral nerves characterized by gradually increasing weakness of the legs and, to a lesser extent, the arms.

It is the gradual onset as well as the *chronic* nature of CIDP that differentiates it from GBS. Fortunately, CIDP is even rarer than GBS. The incidence of new cases is estimated to be between 1.5 and 3.6 in a million people (compare to GBS: 1-2 in 100,000).

Like GBS, CIDP is caused by damage to the covering of the nerves, called *myelin*. It can start at any age and in both genders. Weakness occurs over two or more months.
Unlike GBS, CIDP is not self-limiting (with an end to the acute phase). Left untreated, 30% of CIDP patients will progress to wheelchair dependence. Early recognition and treatment can avoid a significant amount of disability.

Post-treatment life depends on whether the disease was caught early enough to benefit from treatment options. Patients respond in various ways. The gradual onset of CIDP can delay diagnosis by several months or even years, resulting in significant nerve damage that may take several courses of treatment before benefits are seen. The chronic nature of CIDP differentiates long-term care from GBS patients. Adjustments inside the home may need to be made to facilitate a return to normal life.

ABOUT THE FOUNDATION

The Foundation's vision is that every person afflicted with GBS, CIDP, or variants has convenient access to early and accurate diagnosis, appropriate and affordable treatments, and dependable support services.

The Foundation's mission is to improve the quality of life for individuals and families across America affected by GBS, CIDP, and their variants by:

- Providing a network for all patients, their caregivers and families so that GBS or CIDP patients can depend on the Foundation for support, and reliable up-to-date information.
- Providing public and professional educational programs worldwide designed to heighten awareness and improve the understanding and treatment of GBS, CIDP and variants.
- Expanding the Foundation's role in sponsoring research and engaging in patient advocacy.

JIM'S STORY

I had GBS in 1973. This is important because the subject matter, IVIG treatments, were not available in 1973 and I believe that because it was not available, my experience with GBS was many times worse than it needed to be. I was totally paralyzed and only my head was able to move side to side. When the disease hit me, I was a college student in St. John's University in NYC in my fourth year and a newlywed of three months and I was also working thirty hours a week as a night manager in a busy Tire and Auto repair business. My wife and I were just beginning our lives together when GBS struck us down like a lightning bolt. My wife was also working full time and now the care of her totally paralyzed husband was in the hands of a nineteen year woman who was asked to do things and make decisions that no nineteen year old women should have to make. I never finished college due to the amount of medical bills the accumulated and this affected my working life for decades. Keeping in mind the year, 1973, ICU care was very different then it is now. She was only allowed to visit me in the ICU for five minutes every hour. The rest of the time, she spent in a tiny waiting room with other ICU patient's families. She was at the hospital before work, at lunchtime and in the evening totaling about forty minutes a day. Imagine the stress on this young lady. I spent five weeks in the ICU, totally paralyzed with a tracheotomy and with no movement and no ability to communicate in anyway at all. Any need that I had had to be guessed by the four person nursing staff who also had a dozen other very ill patients who were in the open room that held all of these patients. Nights were a nightmare. They were long mostly because I was not sleeping well, day or night. Minutes seemed like hours, and hours seemed like weeks. I was aware all of the time and it was like I was in a glass shell, unable to get out. The hospital staff tried, but no one could understand what it was like to be in that bed. One memorable evening, the tube that was connected to the MA-1 ventilator popped out of my neck and I was not getting any oxygen. Nobody saw that the bellows of the ventilator had dropped down. Someone had to see the situation or I was in big trouble. I had passed out from lack of air. Someone finally saw that it was not breathing for me. The "crash cart" finally got to me and I began to get some air. People started yelling "why didn't the alarm sound" There was an alarm that sounds if the machine failed for any reason. Two D cells powered the alarm and they were dead. Two D cells almost did me in.

I firmly believe that if IVIG was available for me in 1973, I would have never been so paralyzed and in need of a ventilator. My life was in the hands of a hospital staff and machinery and humans who make mistakes. Time and time again, IVIG has arrested the progress of GBS patients and prevented a patient from needing a vent and putting their life in danger. GBS in and of itself generally does not cause a patient to die, it is poor care or a late diagnosis or preexisting conditions. IVIG is a lifesaver and huge factor in reducing the level of paralysis and the amount of time that a patient is in hospital and rehab. I wish that IVIG was available when I had GBS. Its availability would have a huge difference in my case.

CENTERS FOR DISEASE CONTROL AND PREVENTION

CIDP is a progressive condition with serious health impacts. Patients can end up almost completely paralyzed and on a ventilator. The key to limiting serious health impacts is an early and accurate diagnosis. The time it takes for a CIDP patient to begin therapy is linked to the length of therapy and the seriousness of the health impacts. An early diagnosis can mean the difference between a 3 month or 18 month hospital stay, or no hospitalization at all. For the federal healthcare system, there is an economic incentive to ensure early and accurate diagnosis as longer hospitalizations equate to higher costs.

CDC and 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.

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. In fact, NINDS, NIAID, and the Office of Rare Diseases Research (ORDR) housed within NCATS have expressed interest in hosting a State-of-the-Science Conference on autoimmune peripheral neuropathies. This conference would allow intramural and extramural researchers to develop a roadmap that would lead research into these conditions into the next decade. 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.

Thank you for your time and your consideration of the community's requests.

Outside Witness Testimony – Fiscal Year 2017 Appropriations

Submitted by:
WestCare Foundation

Prepared for:
The United States House Committee on Appropriations
Subcommittee on Labor, Health and Human Services, and Education, and Related Agencies

Agencies:
Centers for Disease Control, Substance Abuse and Mental Health Services Administration

April 15, 2016

WestCare Foundation respectfully submits this testimony to the U.S. House Appropriations Subcommittee on Labor, Health and Human Services, and Education, and Related Agencies (LHHS) regarding Fiscal Year (FY) 2017 appropriations for the Center for Disease Control (CDC) Prevention for States Program, a funding request of $80 million, and the Substance Abuse and Mental Health Services Administration (SAMHSA), requesting sufficient funding to address the opioid and prescription drug epidemic.

Each day, 46 people in the United States die from overdose of prescription painkillers[1]. According to the CDC, people in rural communities are nearly twice as likely to overdose on prescription pain medications as people in cities[2]. Prescription drug and opioid abuse is a public health crisis of significant proportion, in which underserved, rural areas are hit the hardest. Offering a full continuum of services to individuals with substance use disorders (SUD), including evidence-based prevention, early intervention and treatment efforts, is a necessary and comprehensive approach to combatting prescription drug overdose and sustaining recovery.

WestCare Foundation is a national non-profit organization that provides a wide array of health and human services in both outpatient and residential environments in nearly 20 States and the Pacific and Caribbean Islands. The Foundation provides comprehensive, wrap-around substance abuse and mental health services for children, adolescents, adults, and families, with an emphasis on serving underrepresented populations in rural areas. WestCare programs have shown significant outcomes in treating veteran and criminal justice populations returning to their communities through recovery supports such as housing, education, employment and other transitional services.

As a national substance use disorder provider, WestCare Foundation recognizes the magnitude of the prescription drug and opioid public health crisis our nation faces, and emphasizes the collaborative role of states, local communities, and service providers in preventing prescription

[1] Center for Disease Control (CDC): http://www.cdc.gov/vitalsigns/opioid-prescribing (2014)
[2] Center for Disease Control (CDC): http://www.cdc.gov/vitalsigns/painkilleroverdoses (2011)

drug overdoses, in addition to the importance of a continuum of care in effectively curbing substance use and mental health disorders through affordable and accessible care.

Center for Disease Control (CDC)

WestCare Foundation supports the Administration's FY 2017 request for $80 million for prescription drug overdose prevention programming at the Centers for Disease Control (CDC), $10 million above FY 2016 enacted levels.

The Center for Disease Control's (CDC) Prescription Drug Overdose Prevention for States Program (Prevention for States) is an initiative implemented in 2015 to provide state health departments with resources and support needed to advance interventions for preventing prescription drug overdoses within four key strategy areas: 1) Enhancing and maximizing state Prescription Drug Monitoring Programs (PDMPs) 2) Implementing community or insurer/health systems interventions 3) Conducting policy evaluations and 4) Developing and implementing rapid response projects. Due to the effectiveness of the program and the rising need, CDC received substantial increases in FY 2015 of $20 million, and in FY 2016, of $50 million dollars, to expand the state prevention activities to a national scale.

To ensure accountability, measurable outcomes and tracked progress, CDC is undergoing an evaluation of the program in order for measures to inform program improvements to achieve the highest public health impact possible as this program continues to grow and expand.

In FY 2017, the President's budget requests $80 million for prescription drug overdose prevention to promote opioid prescribing guideline dissemination and uptake. The Administration's budget proposal includes funding to continue and expand upon state support for Prescription Drug Overdose Prevention Programs in all 50 states and Washington, D.C., and continue to allow rigorous monitoring and evaluation and improvements in data quality.

In Fiscal Year 2017, WestCare Foundation supports the Administration's appropriations request for prescription drug overdose prevention of $80,000,000. This investment will increase accountability for States and allow States to advance and expand interventions for preventing prescription drug overdoses.

Given the prevalence of prescription drug and opioid abuse in rural areas throughout the nation, **WestCare recommends CDC outline a new strategic goal within the Prescription Drug Overdose Prevention for States Program dedicated to rural outreach,** engaging underserved communities through the existing U.S. Department of Agriculture (USDA) Cooperative Extension Service program (Extension Program).

By utilizing existing infrastructure such as Extension Programs, we can build on and connect services already underway such as SAMHSA Block Grants, SAMHSA Drug Free Communities, CDC Prevention for States, and HRSA grantees and streamline federal efforts to increase local and federal collaboration. Lack of local-federal and interagency coordination has impeded efficient, collaborative efforts among local stakeholders.

In February 2016, Secretary Tom Vilsack of USDA announced the "Rural America Opioid Initiative" to address the shortage in substance abuse services in rural areas. This interagency initiative has potential to serve as an effective vehicle in coordinating federal efforts to combat the opioid and heroin public health crisis in rural America. Through interagency coordination between the CDC and USDA, states and local communities can capitalize on existing programs like the USDA Extension Program and the CDC Prevention for States Program. Specifically, WestCare recommends that the CDC Prevention for States Program require grantees to provide Extension Offices with the resources, best practices, and technical expertise necessary to guide and assist local communities and rural SUD treatment providers in expanding treatment capacity and coordinating federal, state, and local opioid initiatives and funding streams at the local level.

WestCare respectfully recommends the following report language be inserted into the Fiscal Year 2017 Labor, Health and Human Services, Education, and Related Agencies Appropriations Bill: "the Committee directs the agency [CDC] to offer a new Prescription Drug Overdose Prevention for States Program competition [in Fiscal Year 2017] that incorporates a strategic goal to implement effective prescription drug overdose prevention in underserved rural areas, provided that up to 2% of funds under the program may be retained for an annual national summit on opioid treatment in rural communities."

Substance Abuse and Mental Health Services Administration (SAMHSA)

In FY 2017, WestCare Foundation supports increased investment to address prescription opioid abuse and heroin use, and is encouraged by the significant attention to substance use disorder treatment expansion, provided that medication-assisted-treatment is coupled with the full continuum of behavioral therapy and recovery support services. As physicians become gate keepers it is also imperative that they are highly qualified in diagnosing behavioral health disorders, treating addiction as a disease, proper pain prescribing, providing person-centered recovery plans, and making appropriate referrals to behavioral health specialists as they would for another health disorder.

WestCare Foundation applauds the Administration's and Congress' attention to the opioid and heroin epidemic, but recommends that any investment in medication-assisted treatment emphasize and provide flexibility for individualized, patient-centered behavioral and recovery support services. Substance addiction is a chronic, relapsing disease with prescribed care regimens that are often comparable to diabetes or heart disease, requiring patient education, treatment, rehabilitation, and consistent management of the disease upon recovery. Treatment modality, length of stay and service provision must be taken into consideration and will vary depending on the duration, dose and type of substance use, as well as the age of first initiation, trauma experienced, and other physical and mental health co-occurring disorders.

As with other chronic conditions treated with medication, medication-assisted treatment may facilitate stabilization and recovery for an opioid disorder. However, similar to a diabetic who receives insulin without changing their behavior and lifestyle through diet and exercise, an individual suffering from opioid addiction who receives medication-assisted treatment without complementary behavioral and recovery support services may not achieve sustained recovery.

Medication-assisted-treatment used in combination with necessary behavioral support services may help substance-addicted individuals to sustain their recovery.

SUDs are present on a wide spectrum of severity, often with co-occurring mental health and primary care health issues. To address the range of issues, WestCare provides differentiated programs across the continuum of care – services to accompany medication-assisted treatment. WestCare's wrap-around services include outpatient and residential treatment programs that include assessment, individual and group counseling, and case management; family and transitional education; vocational education; recreational therapy; health and mental health promotion; permanent and temporary supportive housing; and other community and peer supports.

One of the most pressing barriers to comprehensive services is workforce capacity and access to treatment. People seeking treatment are usually at their lowest point and impressionable. When forced to wait for treatment service, hopelessness can manifest and increase the likelihood for relapse. Unfortunately, the existing community-based system of care for heroin and opioid disorders is restricted by the Institute of Mental Disease (IMD) exclusion at a time when greater capacity is an essential respond to the crisis.

Medication-assisted treatment has been shown to improve patient survival, increase retention in treatment, decrease illicit opiate use and other criminal activity among people with substance use disorders, increase patients' ability to gain and maintain employment, improve birth outcomes among women who have substance use disorders and are pregnant[3].

Despite this evidence-based approach and proven effectiveness, medication-assisted-treatment is greatly underused. According to SAMHSA, the number of heroin admissions with treatment plans that included receiving medication-assisted opioid therapy fell from 35% in 2002 to 28% in 2010[3]. Slow adoption of these treatment options is partly due to misconceptions about substituting one drug for another and lack of training for physicians. Now, medication-assisted treatment is being looked to as a primary and sustainable method to provide comprehensive treatment.

The CDC Guideline for Prescribing Opioids for Chronic Pain released in March of 2016 recommends clinicians "offer or arrange evidence-based treatment (usually medication-assisted treatment with buprenorphine or methadone in combination with behavioral therapies) for patients with an opioid use disorder[4]." As an extension, the CDC points to studies that suggest using behavioral therapies, in combination with treatments like methadone maintenance therapy or buprenorphine, can reduce opioid misuse and increase retention during maintenance therapy and improve compliance after detoxification[5].

As both providers and policy-makers look to medication-assisted treatment models, the importance of behavioral therapy and full recovery support cannot be overstated. Therefore, **WestCare Foundation respectfully requests that any funding appropriated by Congress for medication-assisted treatment include report language explicitly stating "medication-assisted treatment**

---

[3] SAMHSA Treatment Episode Data Set (TEDS) 2002-2010: http://store.samhsa.gov/product/2000-2010-National-Admissions-to-Substance-Abuse-Treatment-Services/SMA12-4701

[4] CDC Guideline for Prescribing Opioids for Chronic Pain — United States, 2016: http://www.cdc.gov/mmwr/volumes/65/rr/rr6501e1.htm

in conjunction with behavioral and recovery support services" as an allowable use of medication-assisted treatment funds. The intention is to provide sufficient flexibility to allow substance use disorder treatment providers to meet local needs of their individual communities and target vulnerable populations such as pregnant women and veterans.

In closing, WestCare Foundation recognizes the fiscal realities of the federal budget but remains encouraged by Congress' strong commitment to addressing our nation's substance abuse public health crisis. We support the highest possible funding for mental health and substance use disorder treatment in FY 2017, and believe that through greater coordination of existing programs we can improve and better document treatment outcomes for people who suffer from addictions and or co-occurring disorders. We strongly encourage the Subcommittee not to overlook the need of coordination, capacity building, and the break-down of federal funding silos at the most local levels, particularly in rural communities. We further urge the Subcommittee not to view medication-assisted treatment as a "silver bullet," quick solution to our nation's opioid public health crisis – medication must be paired with complementary behavioral support services to achieve long-term, sustainable recovery. We look forward to collaborating on the FY 2017 appropriations process as Congress looks to invest and direct resources to this critical, national issue.

Lou Ann Kibbee

Systems Advocacy Manager

Southeast KS Independent Living Resource Center

I am Lou Ann Kibbee, the Systems Advocacy Manager for Southeast KS Independent Living (SKIL) Resource Center based in Parsons, KS. I am writing to support the National Council on Independent Living's request for Congress to reaffirm your commitment to the more than 57 million Americans disabilities by increasing funding in the HHS appropriations for Centers for Independent Living (CILs). I am asking that you increase funding by $200 million, for a total of $301 million for the Independent Living line item in FY 2017.

CILs are cross-disability, non-residential, community-based, nonprofit organizations that are designed and operated by individuals with disabilities. CILs are unique in that they are directly governed and staffed by people with all types of disabilities, including people with mental, physical, sensory, cognitive, and developmental disabilities. Each of the 365 federally funded centers provides five core services: information and referral, individual and systems advocacy, peer support, independent living skills training, and transition services, which were added with the passage of the Workforce Innovation and Opportunity Act (WIOA). From 2012-2014, CILs provided the core services to nearly 5 million people with disabilities, and provided additional services such as housing assistance, transportation, personal care attendants, and employment services to hundreds of thousands of individuals. During this same period, prior to transition being added as a core service, CILs transitioned 13,030 people with disabilities from nursing homes and other institutions into the community. In 2015, Kansas CILs saved the State of KS

over $4M in nursing home costs by assisting individuals to transition out of nursing homes. Additional funds would allow us to transition more individuals. CILs in Kansas provided Independent Living Skills Training, including cooking, budgeting, menu planning, to 2,754 individuals with disabilities. As well as Peer Support services to 1,581 individuals, Information and Referral to 13,454 individuals and their families. We also provided Individual Advocacy to 459 individuals with disabilities in gaining or obtaining goods or rights they are entitled to.

Transition services were added as a fifth core service with the 2014 reauthorization of the Rehabilitation Act within the Workforce Innovation and Opportunity Act. Transition services include the transition of individuals with significant disabilities from nursing homes and other institutions to home and community-based residences with appropriate supports and services, assistance to individuals with significant disabilities at risk of entering institutions to remain in the community, and the transition of youth with significant disabilities to postsecondary life. This core service is vital to achieving full participation for people with disabilities.

Every day, CILs are fighting to ensure that people with disabilities gain and maintain control over our own lives. We know that this cannot occur when people reside in institutional settings. Opponents of deinstitutionalization say that allowing people with disabilities to live in the community will result in harm. We know that the 13,030 people with disabilities who CILs successfully transitioned out of nursing homes and institutions from 2012-2014 prove otherwise. Additionally, when services are delivered in an individual's home, the result is a tremendous cost savings to Medicaid, Medicare, and states. Community-based services enable people with disabilities to become less reliant on long-term government supports, and they are significantly

less expensive than nursing home placements. We are grateful that Congress demonstrated their understanding and support for community-based services when WIOA was passed and transition was added as a fifth core service.

Since transition services were added as a core service, the need for funding is critical. Moreover, CILs need additional funding to restore the devastating cuts to the Independent Living program, make up for inflation costs, and address the increased demand for independent living services. In 2016, the Independent Living Program is receiving $2.5 million less in funding than it was in 2010. It is simply not possible to meet the increasing demand for services and effectively provide transition services without additional funding. Increased funding should be reinvested from the billions currently spent to keep people with disabilities in costly Medicaid nursing homes and institutions and out of mainstream society.

Centers for Independent Living play a crucial role in the lives of people with disabilities, and work tirelessly to ensure that people with disabilities have a real choice in where and how they live, work, and participate in the community. Additionally, CILs are an excellent service and a bargain for America, keeping people engaged with their communities and saving taxpayer money. NCIL is dedicated to increasing the availability of the invaluable and extremely cost-effective services CILs provide, and they have submitted written testimony with a similar request. I strongly support NCIL's testimony.

James Baumberger, on behalf of the Friends of NICHD
Subcommittee on Labor, Health and Human Services, Education, and Related Agencies
National Institutes of Health, National Institute of Child Health and Human Development

My name is James Baumberger. I currently serve as Chair of the Friends of the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD). On behalf of the Friends, I urge the Labor, Health and Human Services, Education, and Related Agencies Appropriations Subcommittee to support at least $34.5 billion for the National Institutes of Health (NIH), including $1.441 billion for NICHD for fiscal year (FY) 2017. Our coalition includes over 100 organizations representing scientists, physicians, health care providers, patients, and parents concerned with the health and welfare of women, children, families, and people with disabilities. We are pleased to support the extraordinary work of NICHD.

Since its establishment in 1963, NICHD has achieved great success in meeting the objectives of its broad biomedical and behavioral research mission, which includes research on child development before and after birth; women's health throughout the life cycle; maternal, child, and family health; learning and language development; reproductive biology; population health; and medical rehabilitation. With sufficient resources, NICHD can build upon the promising initiatives it has undertaken over the last 50 years, produce new insights into human development, and develop solutions to health and developmental problems throughout the world, including individuals and families in your states. Scientific breakthroughs supported by NICHD serve to prevent and treat many of the nation's most devastating health problems including infant mortality and low birthweight, birth defects, intellectual and developmental disabilities, and the reproductive and gynecologic health of women throughout their lifespan. Some of NICHD's research activities are highlighted below.

Zika Virus: NICHD is also now playing a crucial role in research related to the Zika virus. Linked to the development of congenital microcephaly, Zika virus poses a clear threat to mothers and children in the United States and beyond. NICHD is uniquely positioned to investigate the mechanisms that lead to microcephaly during pregnancy and to help uncover medical breakthroughs to mitigate the harmful effects of Zika virus. In fact, NICHD recently funded U.S.-based researchers to conduct a large study of pregnant women in Brazil from the first trimester of pregnancy. The study will track Zika infection in these women and follow children suspected of being affected by the virus for two years.

Preterm Birth: NICHD supports a comprehensive research program to study the causes of preterm birth, prevention strategies, and treatment regimens. Preterm birth costs our nation $26 billion annually and is a leading cause of infant mortality and intellectual and physical disabilities. Continued prioritization of extramural preterm birth prevention research, the Maternal-Fetal Medicine Units Network, the Neonatal Research Network, and the intramural research program related to prematurity are necessary to further this work. Resources should also be available to support transdisciplinary science as recommended in NICHD's Scientific Vision to study and identify the complex causes of preterm birth. NICHD supports research on the causes of preterm birth with the goal of discovering ways to prevent it. Although research has identified some factors that influence preterm birth (e.g., multiple gestation pregnancy, infections, diabetes, high blood pressure, closely spaced pregnancies), it cannot be fully explained by physical health. Robust funding is needed for research to determine the complex interaction of psychological, behavioral, social, and environmental factors, in addition to genetic and biological influences, that causes preterm birth with the ultimate goal of developing

interventions to decrease this epidemic. In addition, a baby is stillborn in the United States every 21 minutes, and NICHD should join with other researchers to establish a research agenda that will lead to better prevention strategies.

National Children's Study (NCS)-Alternative/Environmental Influences on Child Health Outcomes (ECHO) Program: The Children's Health Act of 2000 called for the NIH to evaluate a wide range of environmental influences on the health and development of children. While the National Children's Study was created to accomplish this goal, it was ultimately deemed unfeasible and was closed. However, the child health goals of the Children's Health Act remain as important today as 14 years ago. The President's FY2017 budget includes $165 million within the NIH Office of the Director for a new program called the Environmental Influences on Child Health Outcomes (ECHO) to succeed the NCS. Initially, the ECHO program will fund expansions of existing cohorts to focus on four priority issues for child health: asthma, obesity, neurodevelopmental issues likes autism, and prematurity. The Friends support this request and urge the NIH, with input and participation from NICHD, to undertake this important research project and include the prenatal period to determine the effects of physical and social environments on child health.

Intellectual and Developmental Disabilities Research Centers (IDDRC): Since their inception in the late 1960's, these Centers have been the national resource for basic research into the genetic and biological basis of human brain development, greatly improving our understanding of the causes of developmental disabilities and promoting the development of effective treatments consistent with their translational science mission. However, the Friends are concerned that the IDDRC network does not have sufficient resources to sustain the progress made in this critical area. We urge NICHD to provide additional resources to the IDDRCs for research infrastructure and expansion of cores so that they can conduct basic and translational research to develop effective prevention, treatment, and intervention strategies for children and adults with developmental disabilities.

Population Research: The NICHD Population Dynamics Branch supports a research portfolio investigating how population change affects the health, development, and wellbeing of children and their families. The branch is known for supporting large-scale longitudinal studies, such as the National Longitudinal Study of Adolescent to Adult Health (Add Health), a survey of over 20,000 adolescents who have been followed for 15 years into adulthood. Recent results from Add Health demonstrate how social relationships affect physical health, including chronic disease and longevity. The branch also leads the Fragile Families and Child Wellbeing Study, which follows nearly 5,000 children in large U.S. cities, most born to unmarried parents between 1998 and 2000. The Fragile Families study has demonstrated the role that family stability and parental involvement play in the long-term health and development of children. In 2014, researchers using both genetic and survey data from the study found that poverty and unstable family environments destabilize the DNA of young boys raised in such environments. This finding provides new insights into the insidious role chronic stress plays in child health. In 2015, findings derived from the Fragile Families and Child Wellbeing Study found that paternal engagement can reduce behavioral problems, independent of the mother's characteristics and her level of engagement.

Sex Differences in Research: The Friends encourages NICHD to look at ways to increase data reporting to address gaps in gender and sex differences in research. Sex differences need to be acknowledged as a critical biological variable. In addition to including more women in clinical research, we believe sex differences should be included as part of the design of all basic biological studies and clinical research. If researchers were to consider sex differences in the design of basic science studies, and incorporate data on sex as a biological variable in animal and human studies, more appropriate conclusions could be drawn from basic research and clinical research would provide more representative data on safety and efficacy of drugs.

Clinical Trials in Pregnant Women: Pregnant women have historically been excluded from most research trials due to concern that trial participation could harm the fetus. Although there has been substantial progress in the inclusion of women in federally funded research, pregnant women are still excluded, even from research that would advance our knowledge of medical conditions and treatments in pregnancy. Mindful of the important considerations of clinical trials on pregnant women, we support establishment of a federal work group to propose how clinical research might be done appropriately in this area.

PregSource: The PregSource crowd-sourcing project, to be unveiled in 2016, will allow pregnant women to track their health data from gestation to early infancy as well as access evidence-based information about healthy pregnancies. Unique to this project, however, will be the ability for researchers to connect with NICHD staff to access aggregate data and potentially recruit participants for clinical trials in order to eliminate knowledge gaps and improve care for pregnant and post-partum women.

Data on Pediatric Enrollment in NIH Trials: NIH policy mandates the inclusion of women, minorities, and children in clinical studies whenever appropriate. While NIH collects enrollment data on women and minorities, it does not collect enrollment data on children. We urge Congress to direct the NIH, with leadership from NICHD, to begin tracking the numbers of children, broken down by pediatric age group, enrolled in NIH-funded studies. Better tracking is needed to ensure adequate representation of children in relevant trials.

Best Pharmaceuticals for Children Act (BPCA): Through the BPCA program, NICHD funds the study of drug products that are important to children but have been inadequately studied in pediatric populations. We urge continued funding and support for this important research as well as support for training the next generation of pediatric clinical investigators.

Contraceptive Research and Development: NICHD's Contraceptive Discovery and Development Branch supports basic, applied and clinical research on contraceptive methods. Through its contraceptive evaluation research, NICHD plays a key role in addressing behavioral issues related to fertility and contraceptive use. Specific contraceptive evaluation opportunities and research priorities include evaluation of the safety and effectiveness of hormonal contraceptives for women who are overweight. NICHD's investment in contraceptive research and development is critical for producing new contraceptive modalities that are more effective, affordable, acceptable, and easier to deliver. Specific opportunities and research priorities in this area include the need for non-hormonal contraception, pericoital contraception, and multipurpose prevention technologies that would prevent both pregnancy and sexually transmitted infections.

Reproductive Sciences: Through its investment in reproductive science, NICHD conducts research to improve women's health by developing innovative medical therapies and technologies and improving existing treatment options for gynecological conditions affecting overall health and fertility. NICHD's reproductive science research makes a vital contribution to women's health by focusing on serious conditions that have been overlooked and underfunded, despite the fact that they impact many women. Future work could focus on infertility and the need for treatments for disorders such as endometriosis, polycystic ovarian syndrome (PCOS) and uterine fibroids which can prevent couples from achieving desired pregnancies.

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 approximately 25% of American women. The PFDN is conducting research to improve treatment of these painful conditions. Current research is aimed at improving female urinary incontinence outcome measures and ensuring high quality patient-centered outcomes.

Development of the Research Workforce: Adequate levels of research require a robust research workforce. The years of training combined with funding uncertainty are disincentives for students considering a career in biomedical research. For instance, there is a huge gap between the too-few women's reproductive health researchers being trained and the immense need for research. NICHD's Women's Reproductive Health Research (WRHR) Program and Reproductive Scientist Development Program (RSDP), both aimed at obstetrician-gynecologists to further their education and experience in basic, translational, and clinical research, provide training grants to hundreds of researchers and provide new insight into a host of diseases, such as ovarian cancer. Continued investment in these and other training programs is critical.

Mother-Infant Relationships: NICHD supports multidisciplinary, cutting edge research to advance our understanding of attachment in mother-infant relationships and its impact on development. Early life experiences can have profound impacts on behavioral and health outcomes later in life, but often require specific experimental controls to pinpoint the impacts of various factors. Thus, we urge NICHD to continue support of a robust intramural and extramural research portfolio identifying and describing the complex interaction of behavioral, social, environmental, and genetic factors on health outcomes leading to improved understanding of and interventions for mental illnesses such as depression, addiction, and autism.

Down Syndrome: NICHD-funded investigators have made unprecedented progress toward identifying treatments to reverse or ameliorate the cognitive impairment associated with Down syndrome, as well as understanding how a gene on the 21st chromosome might contribute to the development of Alzheimer's disease in people with Down syndrome. In addition, the NICHD-supported Down Syndrome Registry, DS Connect, has allowed the Down syndrome community to share information and health history in a safe, confidential, online database.

These research efforts have made significant contributions to the well-being of all Americans, but there is still much to discover. We urge you to support NICHD at funding levels that meet current needs for addressing health issues across the lifespan. Thank you for your consideration and we look forward to working with you on these critical issues.

Statement on Behalf of the
American Mosquito Control Association

Submitted to the
House Appropriations Subcommittee on Labor, Health and Human Services, and Education, and Related Agencies
U.S. House of Representatives

Regarding the

Department of Labor

April 15, 2016

Chairman Cole, Ranking Member DeLauro, and members of the Subcommittee, thank you for your continued leadership and support for mosquito control.

The American Mosquito Control Association (AMCA) appreciates this opportunity to submit our views regarding the FY 2017 Labor, Health and Human Services, and Education, and Related Agencies appropriations bill, and respectfully requests this statement be made part of the official hearing record. AMCA is a nonprofit organization of 1600 members dedicated to enhancing health and quality of life through the suppression of mosquitoes and other vectors of public health importance.

With the emergence and spread of the Zika virus in the western hemisphere on the heels of diseases such as dengue, West Nile and chikungunya, it would appear prudent to increase a sustainable nationwide capacity for the surveillance and control of their mosquito vectors. In the absence of vaccines for these diseases, vector control remains the first line of defense. To increase that defense, we ask for your consideration and favorable support for the following appropriations recommendations;

1. Increase the Centers for Disease Control (CDC) – Division of Vector-Borne Diseases (DVBD) annual budget for arbovirus work from its current level of about $26.8 million/year to at least $50 million/year. Of this overall sum, it would be beneficial to ensure that substantial sums are dedicated to on-the-ground activities. AMCA suggests the Committee provide direction in the following manner:

A. $13.75 million for state, county or municipal public health agencies or labs to help support arbovirus **testing and reporting.**

B. $13.75 million for state, county, district or municipal mosquito control programs to help support mosquito control-related **work on the frontlines**.

C. $22.5 million (or 45% of the total) will be kept by the CDC/DVBD to help support myriad arbovirus-related programs and activities at the federal level.

The Epidemiology and Laboratory Capacity (ELC) grant program provides local health jurisdictions with personnel, equipment and resources to detect and respond to mosquito transmitted diseases, but the program in its current state is insufficient to prevent the spread of the Zika virus.

2. Funding for the Mosquito Abatement for Safety and Health Act (MASH) of at least $100,000,000:

The Mosquito Abatement for Safety and Health (MASH) Act was designed to support local government mosquito control activities and was originally passed during the first West Nile Virus outbreak. This bill authorized federal funds for local governments to protect our communities from mosquitoes and other disease vectors. Local program funds were to be matched by federal funding by a ratio of at least 1 to 3 and additional funding was to be for each state to monitor the local program funding. But by the time the MASH Act was signed into law no funds were ever appropriated. Today we face another imminent outbreak of a disease for which mosquito control is the only viable solution. Fortunately, Congress has the means readily at hand to help prevent or minimize the risk, if it chooses to devote dollars to the existing authority.

3. Funding for data collection efforts to support the vector control toolbox: At least $27,000,000:

A. At least $12,000,000 to bolster the Food Quality Protection Act of 1996 (FQPA) that helps retain registrations of existing public health pesticides facing increasingly stringent data collection requirements to prove safety to humans and the environment.

B. At least $15,000,000 to support the development and registration of new vector control tools effective against *Aedes aegypti* and *Aedes albopictus*.

In 1996 Congress unanimously approved FQPA (PL 104-170) to modernize the regulation of pesticides and expand data requirements to demonstrate their safety to people and the environment. A key element was authorization to use federal funds when the cost of new data for public health pesticides – those for mosquitoes and similar disease vectors – was more than their producers could afford, putting registration at risk. Unfortunately, these essential funds have never been appropriated.

Given the federal commitment to ensuring the health of Americans, we believe these small preventative investments are vastly preferable to the enormous health care costs required after

large mosquito-borne disease outbreaks. Establishing sustainable training research and suppression programs for vector-borne disease surveillance and control will ensure a robust capacity to mitigate the impacts of not only the current Zika threat but also dangerous exotic viruses yet to reach our shores.

AMCA thanks you in advance for considering these critical proposals and we urge their inclusion in the pending appropriations process. We sincerely appreciate the opportunity to share our views on these important public health matters.

Claudia Mancera

Program Director

Lake County Center for Independent Living

My name is Claudia Mancera and I am the Program Director at Lake County Center for Independent Living. I am also a person with a disability. I am writing to support the National Council on Independent Living's request for Congress to reaffirm your commitment to the more than 57 million Americans disabilities by increasing funding in the HHS appropriations for Centers for Independent Living (CILs). I am asking that you increase funding by $200 million, for a total of $301 million for the Independent Living line item in FY 2017.

CILs are cross-disability, non-residential, community-based, nonprofit organizations that are designed and operated by individuals with disabilities. CILs are unique in that they are directly governed and staffed by people with all types of disabilities, including people with mental, physical, sensory, cognitive, and developmental disabilities. Each of the 365 federally funded centers provides five core services: information and referral, individual and systems advocacy, peer support, independent living skills training, and transition services, which were added with the passage of the Workforce Innovation and Opportunity Act (WIOA). From 2012-2014, CILs provided the core services to nearly 5 million people with disabilities, and provided additional services such as housing assistance, transportation, personal care attendants, and employment services to hundreds of thousands of individuals. During this same period, prior to transition being added as a core service, CILs transitioned 13,030 people with disabilities from nursing homes and other institutions into the community.

Transition services were added as a fifth core service with the 2014 reauthorization of the Rehabilitation Act within the Workforce Innovation and Opportunity Act. Transition services include the transition of individuals with significant disabilities from nursing homes and other institutions to home and community-based residences with appropriate supports and services, assistance to individuals with significant disabilities at risk of entering institutions to remain in the community, and the transition of youth with significant disabilities to postsecondary life. This core service is vital to achieving full participation for people with disabilities.

Every day, CILs are fighting to ensure that people with disabilities gain and maintain control over our own lives. We know that this cannot occur when people reside in institutional settings. Opponents of deinstitutionalization say that allowing people with disabilities to live in the community will result in harm. We know that the 13,030 people with disabilities who CILs successfully transitioned out of nursing homes and institutions from 2012-2014 prove otherwise. Additionally, when services are delivered in an individual's home, the result is a tremendous cost savings to Medicaid, Medicare, and states. Community-based services enable people with disabilities to become less reliant on long-term government supports, and they are significantly less expensive than nursing home placements. We are grateful that Congress demonstrated their understanding and support for community-based services when WIOA was passed and transition was added as a fifth core service.

Since transition services were added as a core service, the need for funding is critical. Moreover, CILs need additional funding to restore the devastating cuts to the Independent Living program,

make up for inflation costs, and address the increased demand for independent living services. In 2016, the Independent Living Program is receiving $2.5 million less in funding than it was in 2010. It is simply not possible to meet the increasing demand for services and effectively provide transition services without additional funding. Increased funding should be reinvested from the billions currently spent to keep people with disabilities in costly Medicaid nursing homes and institutions and out of mainstream society.

Centers for Independent Living play a crucial role in the lives of people with disabilities, and work tirelessly to ensure that people with disabilities have a real choice in where and how they live, work, and participate in the community. Additionally, CILs are an excellent service and a bargain for America, keeping people engaged with their communities and saving taxpayer money. NCIL is dedicated to increasing the availability of the invaluable and extremely cost-effective services CILs provide, and they have submitted written testimony with a similar request. I strongly support NCIL's testimony.

Thank you for your time and the opportunity to provide my testimony. I invite you to visit our Center for Independent Living and will be more than happy to provide a tour and share with you about the services we provide.

Testimony from Paul Bonta, Chair, National Violence Prevention Network Concerning the Center for Disease Control and Prevention FY2017 Appropriations

Submitted for the Record to the House Appropriations Subcommittee on Labor, Health and Human Services, Education, and Related Agencies – April 15, 2016

Thank you for this opportunity to submit testimony in support of increased funding for the National Violent Death Reporting System (NVDRS), which is administered by the National Center for Injury Prevention and Control at the Centers for Disease Control and Prevention (CDC). The National Violence Prevention Network, a broad and diverse alliance of health and welfare, suicide and violence prevention, and law enforcement advocates supports increasing the FY 2017 funding level to $25 million to allow for nationwide expansion of the NVDRS program including all 50 states, District of Columbia and U.S territories. FY 2016 NVDRS funding is $16 million.

BACKGROUND

Each year, about 57,000 Americans die violent deaths.[1] In addition, an average of 117 people[2] (22 of which are military veterans[3]) take their own lives each day. Violence-related death and injuries cost the United States $107 billion in medical care and loss in productivity.[4]

The NVDRS program makes better use of data that are already being collected by health, law enforcement, and social service agencies. The NVDRS program, in fact, does not require the collection of any new data. Instead it links together information that, when kept in separate compartments, is much less valuable as a tool to characterize and monitor violent deaths. With a clearer picture of why violent deaths occurs, law enforcement, public health officials and others can work together more effectively to identify those at risk and target effective preventive services.

Currently, NVDRS funding levels only allow the program to operate in 32 states[5] with 9 additional states having expressed an interest in joining once new funding becomes available. While NVDRS is beginning to strengthen violence and suicide prevention efforts in the 32 participating states, non-participating states continue to miss out on the benefits of this important public health surveillance program.

NVDRS IN ACTION

Opioid deaths are a serious public health issue. Drug overdose deaths are the leading cause of injury deaths in American.[6] It is important to invest in surveillance of opioid addiction to determine the extent of the problem and implement treatment options and community-based prevention strategies. NVDRS has already proven to be an invaluable tool in many states like Alaska, Indiana and Utah that collect information, through toxicology reports, about prescription-opioid overdose associated with violent deaths. Combined 2010 NVDRS data showed that 24% of violent deaths tested were positive for opiates.[7] Importantly, surveillance is included as one of the primary recommendations in a report published by Johns Hopkins

Bloomberg School of Public Health that promotes an evidence-based response to the prescription-opioid epidemic. [8]

Children are often the most vulnerable as they are dependent on their caregivers during infancy and early childhood. Sadly, NVDRS data has shown that young children are at the greatest risk of homicide in their own homes. Combined NVDRS data from **17 of the 32 states that currently participate in NVDRS,** showed that African American children aged four years and under are more than three times as likely to be victims of homicide than Caucasian children,[9] and that homicides of children aged four and under are most often committed by a parent or caregiver in the home. The data further notes that household items, or "weapons of opportunity," were most commonly used, suggesting that poor stress responses may be factors in these deaths. Knowing the demographics and methods of child homicides can lead to more effective, targeted prevention programs.

Intimate partner violence (IPV) is another issue where NVDRS is proving its value. While IPV has declined along with other trends in crime over the past decade, thousands of Americans still fall victim to it every year. An analysis of intimate partner homicide based on NVDRS data from 16 states shows **that intimate partners represented 80% of intimate partner violence-related homicides victims** and corollary victims (family members, police officers, friends etc…) represented the remaining 20% of victims.[10]

Despite being in its early stages in several states, NVDRS is already providing critical information that is helping law enforcement and public health officials target their resources to those most at risk of intimate partner violence. For example, NVDRS data shows that while occurrences are rare, most murder-suicide victims are current or former intimate partners of the suspect or members of the suspect's family. In addition, NVDRS data indicate that women are about seven times more likely than men to be killed by a spouse, ex-spouse, lover, or former lover, and most of these incidents occurred in the women's homes.[7]

NVDRS & VA SUICIDES

Although it is preventable, every year more than 42,773 Americans die by suicide and another one million Americans attempt it, costing more than $42 billion in lost wages and work productivity.[2] In the United States today, there is no comprehensive national system to track suicides. However, because NVDRS includes information on all violent deaths – including deaths by suicide – the program can be used to develop effective suicide prevention plans at the community, state, and national levels.

A 2015 study showed that 19.9 % of all veteran deaths between 2001 and 2007 were suicide, with male veterans three times as likely as female veterans to commit suicide.[11] The central collection of such data can be of tremendous value for organizations such as the Department of Veterans Affairs that are working to improve their surveillance of suicides. The types of data collected by NVDRS including gender, blood alcohol content, mental health issues and physical health issues can help prevention programs better identify and treat at-risk individuals.

In addition to veteran suicides, NVDRS data has been crucial in many states like Oregon, Utah, New Jersey and North Carolina in understanding the circumstances surrounding elder suicide. This has allowed the states to collaborate locally and implement programs that target those populations at greatest risk.

FEDERAL ROLE NEEDED

At an estimated annual cost of $25 million for full implementation, NVDRS is a relatively low-cost program that yields high-quality results. While state-specific information provides enormous value to local public health and law enforcement officials, data from all 50 states, the U.S. territories and the District of Columbia must be obtained to complete the national picture. Aggregating this additional data will allow us to analyze national trends and also more quickly and accurately determine what factors can lead to violent death so that we can devise and disseminate strategies to address those factors.

STRENGTHENING AND EXPANDING NVDRS IN FY2017

The 2014 Consolidated Appropriations Act recognized the public health utility of NVDRS in preventing violent deaths and increased NVDRS funding by roughly $8 million to facilitate continued expansion of the NVDRS program. The program received an additional $4.7 million in FY2016 for a total of $16 million. The additional $5 million will allow for as many as seven new states to join the current 32 states that participate in NVDRS. The time is now to complete the nation-wide expansion of NVDRS by providing an appropriation of $25 million in FY2017 to place NVDRS in all 50 states and U.S. territories.

We thank you for the opportunity to submit this statement for the record. The investment in NVDRS has already begun to pay off, as NVDRS-funded states are adopting effective violence prevention programs. We believe that national implementation of NVDRS is a wise public health investment that will assist state and national efforts to prevent deaths from domestic violence, veteran suicide, teen suicide, gang violence and other violence that affect communities around the country. We look forward to working with you to complete the nationwide expansion of NVDRS by securing an FY2017 appropriation of $25 million.

References

1. Centers for Disease Control and Prevention . (2015, June 18). *Injury Prevention & Control : Division of Violence Prevention.* Retrieved April 14, 2016, from http://www.cdc.gov/violenceprevention/nvdrs/

2. Americans for Suicide Prevention. (n.d.). *Suicide Statistics*. Retrieved April 14, 2016, from Americans for Suicide Prevention: http://afsp.org/about-suicide/suicide-statistics/

3. Kemp, J., & Bossarte, R. (2013, February). *Suicide Report 2012.* Retrieved April 14, 2016, from Department of Veterans Affairs : http://www.va.gov/opa/docs/suicide-data-report-2012-final.pdf

4. Centers for Disease Control and Prevention . (2015, June 18). *National Violent Death Reporting System - An Overview* . Retrieved 14 2016, April , from National Violent Death Reporting System: http://www.cdc.gov/violenceprevention/pdf/nvdrs_overview-a.pdf

5. Centers for Disease Control and Prevention. (2015, December 15). *National Violent Death Reporting System - State Profiles.* Retrieved April 14, 2016, from A CDC website: http://www.cdc.gov/violenceprevention/nvdrs/stateprofiles.html

6. U.S. Department of Health and Human Services . (2016, April 8). *The U.S. Opioid Epidemic.* Retrieved April 14, 2016, from U.S. Department of Health and Human Services : http://www.hhs.gov/opioids/about-the-epidemic/

7. Centers for Disease Control and Prevention. (2014, January 17). *Surveillance for Violent Deaths —National Violent Death Reporting System, 16 States, 2010.* Retrieved April 14, 2016, from Morbidity and Mortality Weekly Report -Surveillance Summaries/ Volume 63/No.1: http://www.cdc.gov/mmwr/pdf/ss/ss6301.pdf

8. Alexander GC, F. S. (2015). *The Prescription Opioid Epidemic: An Evidence-Based Approach.* Baltimore : Johns Hopkins Bloomberg School of Public Health. http://www.jhsph.edu/research/centers-and-institutes/center-for-drug-safety-and-effectiveness/opioid-epidemic-town-hall-2015/2015-prescription-opioid-epidemic-report.pdf

9. Center for Disease Control and Prevention. (2013). *National Violent Death Reporting System* . Retrieved April 14, 2014, from A Web-based Injury Statistics Query and Reporting System (WISQARS) Database: https://wisqars.cdc.gov:8443/nvdrs/nvdrsDisplay.jsp

10. Smith, S. G., Fowler, K. A., & and Niolon, P. H. (March 2014). Intimate Partner Homicide and Corollary Victims in 16 States - NVDRS 2003-2009. *American Journal of Public Health*, 461-466.

11. Kang, H., Bullman, T. A., & Smolenski, D. J. (2015). Suicide risk among 1.3 million veterans who were on active duty during the Iraq and Afghanistan wars. *Annals of Epidemiology*, 96-100.

Outside Witness Testimony of
Ellie Hollander, President and CEO, Meals on Wheels America
Submitted to the Subcommittee on Labor, Health and Human Services, Education and Related Agencies
Committee on Appropriations, U.S. House of Representatives
Relating to Fiscal Year 2017 Appropriations, Administration for Community Living

April, 15 2016

Chairman Cole and Ranking Member DeLauro:

Thank you for allowing me, Ellie Hollander, President and CEO of Meals on Wheels America, the opportunity to present testimony to your Subcommittee concerning Fiscal Year (FY) 2017 appropriations for Older Americans Act (OAA) Nutrition Programs administered by the Administration for Community Living (ACL)/Administration on Aging (AoA) within the U.S. Department of Health and Human Services. On behalf of the more than 5,000 Meals on Wheels programs – both congregate and home-delivered – in communities across the country, we are sincerely grateful for your ongoing support for these proven and effective programs, including the more than $20 million increase provided in H.R. 2029, the Consolidated Appropriations Act of 2015. We urge you to continue to build on the bipartisan, bicameral support that exists for these vital programs and adopt the funding levels included in the President's FY 2017 Budget Request to Congress. For the three OAA Nutrition Programs authorized under Title III of the Act, that request is as follows:

- Congregate Nutrition Services (Title III, C-1) – $454 million
- Home-Delivered Nutrition Services (Title III, C-2) – $234 million
- Nutrition Services Incentive Program (Title III, NSIP) – $160 million

At this critical juncture in our nation's history, when both the need and demand are already substantial and will continue to climb exponentially, we ask that you to give this request your utmost consideration due to the significant social and economic benefits that OAA Nutrition Programs offer. These programs represent one of the best examples of a successful public-private partnership, leveraging about $3 for every $1 appropriated though the OAA, as well as an army of two million volunteers to support their operations and reach more seniors in need. The nutritious meals, friendly visits, and safety and wellness checks these programs deliver each day are providing an efficient and vital support service for our most vulnerable seniors, our families, our communities and taxpayers as a whole. OAA Nutrition Programs (both congregate and home-delivered) enable seniors to live more nourished and independent lives longer in their own homes – where they want to be – reducing unnecessary visits to the emergency room, admissions

and readmissions to hospitals and premature institutionalization. Not only are they providing more than just a meal to those who are fortunate enough to receive their services, but these programs are also an essential part of the solution to our nation's fiscal and demographic challenges.

SERVING THE MOST VULNERABLE

For more than 50 years in communities large and small, urban and rural, OAA Nutrition Programs have been effectively serving seniors in the greatest economic and social need. What started as a demonstration project has grown into a highly effective community-based, nationwide network of more than 5,000 local programs. The federal dollars authorized under Title III of the Act provide a pivotal foundation on which to leverage additional state, local and private resources to serve more seniors in need – those who are frail, isolated, and at significant risk of hunger and losing their ability to live in their home. Data from ACL's State Program Reports and National Survey of OAA Participants demonstrates that the seniors receiving meals at home and in congregate settings, such as senior centers, need these services to remain healthier and independent. They are primarily women, age 75 or older, who live alone. Additionally, they have multiple chronic conditions, take six or more medications daily, are functionally impaired, and the single meal provided through the OAA Nutrition Program represents half or more of their total daily food intake. Significant numbers of seniors are impoverished, live in rural areas, and belong to a minority group. In short, the individuals served through the OAA nutrition network are high risk and potentially high cost to Medicare and Medicaid.

Furthermore, findings from a ground-breaking 2015 study entitled *More Than a Meal*, conducted by Meals on Wheels America in conjunction with Brown University and AARP Foundation, found that those receiving and/or requesting Meals on Wheels services are significantly more vulnerable compared to a nationally representative sample of comparably aged Americans. Specifically, seniors on Meals on Wheels waiting lists were significantly more likely to:

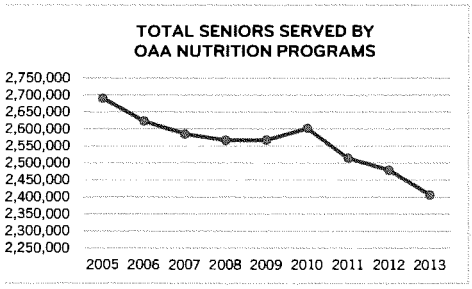
- Report poorer self-rated health (71% vs. 26%)
- Screen positive for depression (28% vs. 14%) and anxiety (31% vs. 16%)
- Report recent falls (27% vs. 10%) and fear of falling that limited their ability to stay active (79% vs 42%)

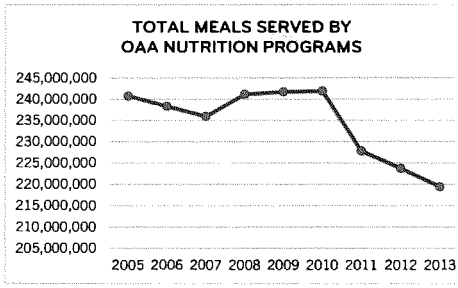
DEFINING THE MAGNITUDE OF THE PROBLEM

Regardless of what statistic you see, it is undeniable that the problem of senior hunger is grave, growing and expensive. Today, 9.6 million seniors – or one in six – may not know from where their next meal will come. Since the start of the recession in 2007 to 2013, the number of seniors age 60 or older experiencing "very low food security" – or "hunger" as expressed by the National Commission on Hunger – has increased by 63%. In 2013, the last year for which we have data from ACL, funding provided through the OAA supported the provision of meals to fewer than 2.5 million seniors nationwide.

Tragically, the gaps continue to widen between the number of seniors struggling with hunger and those receiving nutritious meals through the OAA. Funding for the OAA has simply not kept pace with inflation or need.

In fact, a Government Accountability Office report released last summer found that about 83% of food insecure seniors and 83% of physically impaired seniors did not receive meals [through the OAA], but likely needed them. Currently, the OAA network overall is serving 21 million fewer meals annually to seniors in need than we were in 2005 due to declining federal and state grants, stagnant private funding, and rising food and, transportation and other operational costs. At a minimum, we must stave off this continuous decline not only for the health of our seniors, but for the health of our nation at large. The graphs below illustrate this troubling trend.





Source: Older Americans Act (OAA) Title III Programs data derived from the AGing Integrated Database (AGID) system, the AGID State Profiles. Full reports available at: www.agidnet.acl.gov

PRESENTING THE ECONOMIC CASE

We all know that without proper nutrition, one's health deteriorates and inevitably fails. It is extremely costly not only in personal terms for the individuals who struggle, but also for taxpayers in terms of increased healthcare costs. For seniors, even a slight reduction in nutritional intake can exacerbate existing health conditions, accelerate physical impairment, impede recovery from illness, injury or surgery, and increase the risk of chronic disease(s). The good news is that the infrastructure already exists to meet the escalating nutritional needs of seniors, if adequately funded. Evidence continues to build that proves that bolstering funding for OAA Nutrition Programs will substantially reduce healthcare costs – both in the short- and long-term. On average, a program can deliver Meals on Wheels to a senior for an entire year for about the same cost as just one day in the hospital or ten days in a nursing home – costs that are often incurred by Medicare and Medicaid and for which taxpayers foot the bill.

The aforementioned *More Than a Meal* study found that those who received daily home-delivered meals (the traditional Meals on Wheels model of a daily, in-home-delivered meal, friendly visit and safety check), experienced the greatest improvements in health and quality of life. Specifically, between baseline and follow-up, seniors receiving daily home-delivered meals were more likely to exhibit:

- Improvement in mental health (i.e., levels of anxiety)
- Improvement in self-rated health
- Reductions in the rate of falls and the fear of falling
- Improvement in feelings of isolation and loneliness
- Decreases in worry about being able to remain in home

Further, in addition to being a preventative measure for ER visits and hospital admissions, investing in home-delivered meals is also a proven way to reduce hospital readmissions and post-discharge costs. For example, Meals on Wheels America worked with a national insurer over a five year span, covering more than 135,000 Medicare Advantage seniors post-discharge across 36 states. While this intervention involved just a one-time delivery of ten frozen meals and follow-up phone calls, it produced significant results including average overall healthcare savings of 31% per member per month (PMPM) for the first month following discharge and referral opportunities for about 30% of recipients for ongoing meal and other needed community services. Subsequent engagements have shown that daily meal delivery over a longer period of time (30 days – 6 months or more) produced even more favorable health outcomes and longer term cost savings when compared to national readmission rates. In addition, across six pilots funded by Meals on Wheels America in CA, KS, NC, OH, ME and TX, the average reduction in 30 day readmission rates ranged from 6%-7% as compared to national readmission rates of 15%-33% over the same period.

SCALING THE SOLUTION

It is clear that those who are in need of home-delivered meal services represent our nation's most frail and vulnerable senior population. This is a group with significant health and social support needs. The *More Than a Meal* study reinforces the wealth of past research, indicating that home-delivered meals improve the health and well-being of older adults, particularly for those who receive daily home-delivered meals and live alone. By decreasing feelings of isolation and loneliness and reducing the rate of falls, the research suggests that the traditional Meals on Wheels service delivery model has the greatest potential to decrease healthcare costs. When reviewing the reduction in falls alone, which adjusted for inflation equaled $34 billion in direct medical costs in 2013, further investments in OAA Nutrition Programs are an untapped solution and have the potential to produce billions of dollars in savings to the Mandatory side of the budget.

We certainly understand the difficult decisions you and your colleagues are tasked with in FY 2017 and beyond. However, the evidence proves that these programs are not only saving lives and taxpayer dollars every day, but they are effectively reaching our nation's

most at-risk seniors and have the capacity to serve significantly more, if properly resourced. As such, we hope that you recognize the need to invest further in Discretionary programs, like OAA Nutrition Programs, as they help prevent and mitigate the effects of chronic diseases, improve quality of life, expedite recovery after an illness, injury, surgery or treatment, and reduce unnecessary Medicare and Medicaid expenses both today and in the future.

As your Subcommittee crafts and considers the FY 2017 Labor-HHS-Education Appropriations Bill, we ask that you provide the funding levels included in the President's FY 2017 Budget Request to Congress for all three nutrition programs authorized under the OAA: Congregate Nutrition Program, Home-Delivered Nutrition Program and the Nutrition Services Incentive Program. You have the ability to eliminate waiting lists altogether and to increase the number of nutritious meals we can serve to seniors today. By doing so, you will be investing in a stronger fiscal path for our country by reducing future healthcare costs. Given the magnitude of the senior hunger problem, the time to act is now.

Thank you for your leadership and continued support through the appropriations process, as well as your efforts to ensure passage of S. 192, the Older Americans Act Reauthorization Act of 2016. We hope our testimony has been instructive and are pleased to offer our assistance and expertise at any time throughout this process.

DHHS National Institutes of Health (NIH) FY2017 Budget Appropriations
Request for research on facioscapulohumeral muscular dystrophy (FSHD)
Witness appearing before the
House Appropriations Subcommittee on Labor, HHS, Education and Related Agencies
Daniel Paul Perez, President & CEO, FSH Society April 15, 2016

Agency: *National Institutes of Health (NIH).* ***Account:*** *The NIH; National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS), National Institute of Neurological Disorders and Stroke (NINDS), Eunice Kennedy Shriver National, Institute of Child Health and Human Development (NICHD), National Human Genome Research Institute (NHGRI) and other institutes.*
FY 2017 Report Language: *The Committee strongly encourages the NIH to accelerate research efforts and significantly increase projects and funding on facioscapulohumeral muscular dystrophy (FSHD). The Committee hopes and recognizes that scientific opportunities and recent epigenetic breakthroughs in FSHD will help NIH access therapies for this and many other grave diseases such as cancer.*

Honorable Chairman Cole, Ranking Member DeLauro, and distinguished Members of the Subcommittee, thank you for the opportunity to submit this testimony. It is an honor to have the opportunity to present the (FY) 2017 request for NIH funding for research on facioscapulohumeral muscular dystrophy (FSHD) and update you on scientific opportunities. We thank this subcommittee for making research funding a national priority and for its strong investment in the NIH with the $2 billion funding increase in the FY 2016 Omnibus Appropriation bill.

About FSHD, about our disease, my disease. FSHD, a heritable disease, is among the most common forms of muscular dystrophy with a prevalence of 1:8,000 [1], affecting approximately 870,000 children and adults of both sexes worldwide. It can affect multiple generations and entire families. FSHD is characterized by the progressive loss of muscle strength. Muscle weakness typically starts at the face, shoulder girdle and upper arms, often progressing to the legs, torso and other muscles. The symptoms can develop at any age. The progression of FSHD is highly variable. FSHD has a high burden of disease and can cause significant disability and, in severely affected individuals, premature death, mainly through respiratory failure. Around 20% of affected individuals use a wheelchair or scooter. Besides muscle weakness, FSHD can also have the following manifestations: high-frequency sensorineural hearing loss, respiratory insufficiency, abnormalities of blood vessels in the back of the eye, and non-symptomatic cardiac arrhythmias.

The National Institutes of Health (NIH) is the principal worldwide source of funding of research on FSHD currently at the $8.398 million level FY2015 actual (and $12.616 million FY2016 current), a fraction of the $77 million FY2015 actual it spent on all of the muscular dystrophies. For two decades, this Subcommittee has supported the incremental growth in funding for FSHD research. I am pleased to report that this investment has produced remarkable results and remarkable advances in scientific understanding of human diseases.

A partnership of Congress, NIH, patients and scientists has made truly outstanding progress in identifying areas in need of funding and in communicating these objectives to the public. Congress is responsible for this success by its sustaining support of the overall NIH budget, and specifically through the enactment of the Muscular Dystrophy Community Assistance, Research and Education Amendments of 2001 (MD-CARE Act, Public Law 107-84).

Patients, professionals, and other parties interested in FSHD can contact us at FSH Society, Inc., 450 Bedford Street, Lexington, MA 02420 USA.
p: (781) 275-7781, f:: (781) 275-7789, e: daniel.perez@fshsociety.org. Full testimony with footnotes references at http://www.fshsociety.org

Several days ago, NIH leadership and staff that oversees muscular dystrophy published an editorial in *Muscle & Nerve* describing the work of the truly collaborative Muscular Dystrophy Coordinating Committee (MDCC), mandated by the MD CARE Act, which publicizes the 2015 NIH Action Plan for the Muscular Dystrophies as the roadmap for all funding, patient, family, and research communities. [2] The eighty-one objectives of the Action Plan, released in November, are organized within six sections: mechanism, screening, treatments, trial readiness, access to care, infrastructure including workforce. I have been very involved in creating the MD CARE Act, remain of service to the MDCC, and helped draft, write and edit the first and revised Action Plans. NIH leadership, program and grant review staff have our highest respect and I echo Stephen I. Katz, M.D., Ph.D., chair of the MDCC, director of the NIAMS at the NIH when he says we can all use this plan "to guide research, collaborations and strategies to extend and improve the quality of life of people suffering from these disorders." We are aware that MD Care Act does not set the amount of spending on FSHD or the other dystrophies at the NIH and we recognize that funding levels are determined in the appropriations process and the numbers of grant applications received and funded by the NIH on FSHD. We hope there are additional efforts and pathways that Congress can request and the NIH can enact to increase the amount of research funding on FSHD in the NIH portfolio that neither increases the NIH budget required nor takes money from another area of research and achieves more efficiency out of a non-growing research budget.

As tiny as it is, the FSH Society continues to deliver huge results in improving our understanding of FSHD -- and in turn helping scientists be more competitive at NIH with respect to the grant application and review process. As the nation's most expert and largest FSHD research funding non-profit, the FSH Society's mission is to conduct research, increase awareness, understanding and education on FSHD. While we remain ever curious about how FSHD works, our goal is to improve health, reduce disability and illness and lengthen life for those living with FSHD. As of April 13, 2016, the FSH Society has provided approximately $6.97 million, since the inception of its research fellowships and grants program, in seed funds and grants to pioneering FSHD research areas and education worldwide and created an international collaborative network of patients and researchers. Recent advances in understanding the molecular genetics and cellular biology of FSHD have led to the identification of potential therapeutic targets. Impressive scientific progress was again achieved in 2015 in the basic molecular and clinical understanding of the disease largely due to cumulative Society funding of research. In 2015, the Society issued twelve new grants and fellowships, continued funding five ongoing grants, and issued three travel grants to facilitate travel for professionals working on FSHD. The Society also works with various research institutions doing clinical research on FSHD to help facilitate patient travel for evaluation and tissue and blood donation by covering patient travel and lodging expenses. Dollar for dollar the Society is one of the best investments one can make in FSHD research funding outside of NIH funding and we have been effective and successful stewards of the resources we have been given by our donors to provide individuals, data and new hypotheses of extraordinary quality that the NIH can fund research on FSHD.

Quantum leaps in our understanding of FSHD. The past year and one-half has brought forth exceptional if not remarkable contributions made by a very small but extremely dedicated tribe of researchers funded by the Society, NIH and other non-profits.

Patients, professionals, and other parties interested in FSHD can contact us at FSH Society, Inc., 450 Bedford Street, Lexington, MA 02420 USA. p: (781) 275-7781, f:: (781) 275-7789, e: daniel.perez@fshsociety.org. Full testimony with footnotes references at http://www.fshsociety.org

- On September 25, 2014, researchers from United States, France, Spain, Netherlands and United Kingdom narrow the focus mechanistically opening the possibility of all types of FSHD having an epigenetic basis. [3]
- On March 29, 2015, different researchers involved with the NIH Senator Paul A. Wellstone Cooperative Research Center using its large collection of different FSHD patient samples and different techniques arrive at the same answer that there is an underlying principle of epigenetics defining asymptomatic or non-manifesting and playing a role in disease severity. [4]
- On September 1, 2015, researchers from Fred Hutchinson Cancer Research Center, Seattle, Rochester, New York and the Netherlands funded by a NIH P01 program project describe the role of siRNA-directed AGO/DICER-dependent epigenetic repression (silencing the DUX4 retrogene with the D4Z4 region) showing a pathway to therapeutically target FSHD. [5]
- On November 3, 2015, researchers at the University of Massachusetts Medical School (UMMS) successfully used a derivation of the CRISPR-based gene-editing method known as dCas9 to target and silence the DNA sequence implicated in FSHD. For the very first time a CRISPR-based system was been used to ameliorate pathogenic gene expression in FSHD successfully in primary human muscle cells. [6]
- On March 6, 2016 researchers at the University of Minnesota define an important function of the C-terminal domain of DUX4, namely to recruit the acetyltransferases p300 and CBP, which modify chromatin in the vicinity of DUX4 binding. [7]

Many of these findings have their origins in seed funding from the FSH Society to researchers who have then used preliminary data to secure funding from the NIH. We are thrilled that our grantees and colleagues have data and publications that prove that the FSHD-causing DUX4-fl and cascading events can be turned off. Also in this last year in clinical and preclinical research multiple groundbreaking papers have emerged in whole body MRI, xenograph and transgenic/Cre-lox mouse models, improved diagnostic testing, biomarkers and clinical aspects of FSHD and the very first evidenced based guideline were written, compiled and distributed by the Centers for Disease Control, American Academy of Neurology and FSH Society. [3, 8, 9, 10, 11] Despite this, the FSHD research and clinical enterprise is still starved for federal funding from NIH!

We must keep moving forward. In October 2015 the FSH Society held its annual FSHD International Research Consortium meeting in Boston, Massachusetts. The meeting was funded in part by the NIH NICHD University of Massachusetts Medical School Wellstone center for FSHD. Over 100 researchers from around the world gathered to present latest data and discuss research strategies. Areas defined by the FSHD clinical and research community as priority areas are as follows:

Table 1.

Genetics and epigenetics

Priority 1: Continued identification of the parameters that determine disease severity and progression, including identification of additional modifier and disease loci.

Priority 2: Improved diagnostic tests and tests to better predict onset and severity.

Mechanisms and targets

Priority 3: Determine the major mechanism(s) of muscle damage caused by DUX4 expression. DUX4 in muscle activates a diverse panel of pathways and mechanisms, which individually, or combined lead to muscle pathology.

Patients, professionals, and other parties interested in FSHD can contact us at FSH Society, Inc., 450 Bedford Street, Lexington, MA 02420 USA. p: (781) 275-7781, f:: (781) 275-7789, e: daniel.perez@fshsociety.org. Full testimony with footnotes references at http://www.fshsociety.org

Priority 4: Determine the relationship between DUX4 expression and disease onset and progression.
Priority 5: Determine how the expression of DUX4 in one muscle cell nucleus results in the spread of the pathology throughout the muscle.

Models

Priority 6: Continued development and validation of pre-clinical models to test specific pre-clinical goals.

Clinical and therapeutic studies

Priority 7: Validation of subjective and objective measurements of disease onset and progression. Quality of life, muscle function measurements and other physical biomarkers, molecular biomarkers, and imaging biomarkers all show tremendous promise. Individual and cooperative studies to identify, validate, and determine the best standard measurements are critical for trial preparedness in FSHD.

The detailed priorities stated for 2016, at the October 5-6, 2015, FSH Society FSHD IRC meetings can be found at: http://www.fshsociety.org/international-research-consortium/ . We need to be prepared for this new era in the science of FSHD. Many leading experts are now turning to work on FSHD because it represents the potential for great discoveries, insights into stem cells, transcriptional processes, new ways of thinking about disease of epigenetic etiology, and for treating diseases with epigenetic origin.

NIH Funding for Muscular Dystrophy. Mr. Chairman, these major advances in scientific understanding and epidemiological surveillance are not free. They come at a cost. Since Congress passed the MD CARE Act in 2001, research funding at NIH for muscular dystrophy has increased 4-fold (from $21M). While FSHD research funding has increased 16-fold FY2015 (from $0.5M) during this period, the level of funding is still too underpowered for FSHD given the remarkable discoveries in the past six years.

FSHD Research Dollars (in millions) & FSHD as a Percentage of Total NIH Muscular Dystrophy Funding
Sources: NIH/OD Budget Office & NIH OCPL & NIH RePORT RCDC (e = estimate)

Fiscal Year	**2005**	**2006**	**2007**	**2008**	**2009**	**2010**	**2011**	**2012**	**2013**	**2014**	**2015**	**2016e**	**2017e**
All MD ($ millions)	$39.5	$39.9	$47.2	$56	$83	$86	$75	$75	$76	$78	$77	$80	$80
FSHD ($ millions)	$2.0	$1.7	$3	$3	$5	$6	$6	$5	$5	$7	$8	$9	$9
FSHD (% total MD)	5%	4%	5%	5%	6%	7%	8%	7%	7%	9%	10%	11%	11%

Despite the great success of the past six years in the science of FSHD brought about by Congress, NIH, non-profit funding agencies, patients, families and researchers we are gravely concerned that FSHD research is too under-represented in the NIH portfolio. Though in our story DUX4 is inappropriately expressed in the context of muscle only and is harmful in FSHD; there now are several papers in the last month showing DUX4 at work in other diseases and conditions -- in the out layer of skin it is harmful to keratinocytes and in another context of gene fusions it causes cells to divide uncontrollably and cause cancer (B cell acute lymphoblastic leukemia). [12, 13] The extraordinary depth and impact of discovery should soon allow a flood of new talent and higher quality and completive proposals to help NIH redress the imbalance of funding in the FSH muscular dystrophy portfolio by fostering opportunities for multidisciplinary research on FSHD commensurate with its prevalence and disease burden. We are concerned, very concerned that economy of scale is so different in particular for FSHD within the muscular dystrophy funding group. There are no quotas on peer-reviewed research above pay line at the NIH and given now that all the requisites are in place –funding for FSHD should increase rapidly at this time.

There are 32 active projects NIH-wide totaling $12.616 million as of April 14, 2016 versus 26 on March 12, 2015 (source: NIH Research Portfolio Online Reporting Tools (RePORT)

Patients, professionals, and other parties interested in FSHD can contact us at FSH Society, Inc., 450 Bedford Street, Lexington, MA 02420 USA.
p: (781) 275-7781, f:: (781) 275-7789, e: daniel.perez@fshsociety.org. Full testimony with footnotes references at http://www.fshsociety.org

http://report.nih.gov keyword 'FSHD or facioscapulohumeral or DUX4') the 32 projects cover 2 F32, 1 K22, 1 K23, 1 R03, 4 R21, 15 R01, 1 P01, and 2 U54 grants. It was back in 2010, that the NIH Director Dr. Francis Collins said "If we were thinking of a collection of the genome's greatest hits, this [FSHD] would go on the list." [14] In the last year alone, incredible opportunities for public, private and non-profit entities engaged in FSHD research and clinical research have emerged. Oddly these discoveries clearly belonging to the leading edge of human genetics and our understanding the epigenome and treating epigenetic diseases are sitting somewhat idle in the context of federal research funding. NIH needs to maximize research funding by capitalizing on the low hanging fruit that FSHD presents as a gateway to treating human epigenetic disease.

We request for FY2017, a doubling of the NIH FSHD research portfolio to at least $24 million. This will allow an expansion of basic research awards, expansion of post-doctoral and clinical training fellowships, dedicated centers to design and conduct clinical trials on FSHD and more U.S. DHHS NIH Senator Paul D. Wellstone Muscular Dystrophy Cooperative Research Centers, and NIH has conveyed to researchers that it has a revised plan and an interest in funding research in FSHD and muscular dystrophy. Mr. Chairman, thank you for this opportunity to testify before your committee.

Footnotes:

1. Deenen JC, et al, Population-based incidence and prevalence of FSHD. *Neurology*. 2014 Sep 16;83(12):1056-9. Epub 2014 Aug 13.
2. Rieff HI, Katz SI et al. The Muscular Dystrophy Coordinating Committee Action Plan for the Muscular Dystrophies. *Muscle Nerve*. 2016 Mar 21. [Epub ahead of print]
3. Lemmers RJ, et al. Inter-individual differences in CpG methylation at D4Z4 correlate with clinical variability in FSHD1 and FSHD2. *Hum Mol Genet*. 2015 Feb 1;24(3):659-69. Epub 2014 Sep 25.
4. Jones, TI, et al. Individual epigenetic status of the pathogenic D4Z4 macrosatellite correlates with disease in facioscapulohumeral muscular dystrophy. *Clinical Epigenetics* 2015, 72-6, 29 March 2015
5. Lim JW, et al. DICER/AGO-dependent epigenetic silencing of D4Z4 repeats enhanced by exogenous siRNA suggests mechanisms and therapies for FSHD. *Hum Mol Genet*. 2015 Sep 1;24(17):4817-28.
6. Himeda CL, Jones, et al. CRISPR/dCas9-mediated Transcriptional Inhibition Ameliorates the Epigenetic Dysregulation at D4Z4 and Represses DUX4-fl in FSH Muscular Dystrophy. *Mol Ther*. 2016 Mar;24(3):527-35. epub 2015 Nov 3.
7. Choi SH, et al. DUX4 recruits p300/CBP through its C-terminus and induces global H3K27 acetylation changes. *Nucleic Acids Res*. 2016 6 Mar [Epub ahead of print]
8. Tawil R, et al. Evidence-based guideline summary: Evaluation, diagnosis, and management of FSHD: Report of the Guideline Development, Dissemination, and Implementation Subcommittee of the American Academy of Neurology and the Practice Issues Review Panel of the American Association of Neuromuscular & Electrodiagnostic Medicine. *Neurology*. 2015 Jul 28;85(4):357-64.
9. Leung DG, et al. Whole-body magnetic resonance imaging evaluation of facioscapulohumeral muscular dystrophy. *Muscle Nerve*. 2015 Oct;52(4):512-20. Epub 2015 Mar 31.
10. Sakellariou P, Bloch R, et al. Neuromuscular electrical stimulation promotes development in mice of mature human muscle from immortalized human myoblasts. *Skelet Muscle*. 2016 Feb 27;6:4. eCollection 2015.
11. Calandra P, et al. Allele-specific DNA hypomethylation characterises FSHD1 and FSHD2. *J Med Genet*. 2016 Feb 1. pii: jmedgenet-2015-103436. [Epub ahead of print]
12. Gannon OM, et al. DUX4 Is Derepressed in Late-Differentiating Keratinocytes in Conjunction with Loss of H3K9me3 Epigenetic Repression. *J Invest Dermatol*. 2016 Feb 9. pii: S0022-202X(16)00464-4. [Epub ahead of print]
13. Yasuda T, et al. Recurrent DUX4 fusions in B cell acute lymphoblastic leukemia of adolescents and young adults. *Nat Genet*. 2016 Mar 28. doi: 10.1038/ng.3535. [Epub ahead of print]
14. Kolata, G., Reanimated 'Junk' DNA Is Found to Cause Disease. *New York Times*, Science. Published online: August 19, 2010 http://www.nytimes.com/2010/08/20/science/20gene.html

Patients, professionals, and other parties interested in FSHD can contact us at FSH Society, Inc., 450 Bedford Street, Lexington, MA 02420 USA. p: (781) 275-7781, f:: (781) 275-7789, e: daniel.perez@fshsociety.org. Full testimony with footnotes references at http://www.fshsociety.org

CHILDREN'S HOSPITAL ASSOCIATION

Champions for Children's Health

Testimony for the Record

In support of FY 2017 funding for the Children's Hospitals Graduate Medical Education Program (CHGME)

Submitted to the Subcommittee on Labor, Health and Human Services, Education and Related Agencies, House Committee on Appropriations – April 15, 2016

The Children's Hospitals Graduate Medical Education (CHGME) program is administered by the Bureau of Health Workforce in the Health Resources and Services Administration at the Department of Health and Human Services. The statement testimony focuses on the purpose of CHGME and its benefit to all children. The testimony includes a request for the subcommittee to appropriate $300 million for CHGME in Fiscal Year 2017.

The Children's Hospital Association advances child health through innovation in the quality, cost and delivery of care. Representing more than 220 institutions, the Association is the voice of children's hospitals nationally. As organizations dedicated to protecting and advancing the health of America's children, we thank the Subcommittee for its longstanding bipartisan support of the Children's Hospital Graduate Medical Education program (CHGME).

A robust pediatric workforce is essential to ensuring that no child lacks access to high quality medical care. The CHGME program supports this goal by providing funding for the training of pediatric providers at independent children's teaching hospitals, much as Medicare supports training in teaching hospitals that serve primarily adults. CHGME benefits all children, supporting the training of doctors who go on to care for children living in every state — in cities, rural communities, suburbs and everywhere in between.

600 13th Street, NW | Suite 500 | Washington, D.C. 20005 | 202-753-5500
6803 West 64th Street | Overland Park, KS 66202 | 913-262-1436
www.childrenshospitals.org | © Children's Hospital Association

For FY 2016, Congress provided $295 million for CHGME, the program's first funding increase since FY 2010. Children's hospitals are extremely grateful to the Subcommittee for this strong commitment to the health of America's children. For FY 2017, **the Children's Hospitals Association urges the Subcommittee to continue to advance children's health and fund CHGME at its authorized level of $300 million.**

Congress created CHGME in 1999 with bipartisan support because it recognized that the absence of dedicated GME funding for freestanding children's teaching hospitals created gaps in the training of pediatric providers, which potentially threatened access to care for children. Since then, the CHGME program has had a tremendous impact. Although the 58 hospitals that currently receive CHGME funding comprise only 1 percent of all hospitals, they train approximately half (49 percent) of all pediatric residents—more than 6,000 annually—including 45 percent of all general pediatricians and 51 percent of all pediatric specialists.

CHGME has enabled children's hospitals to increase their overall training by more than 45 percent since the program began in 1999. In addition, the CHGME program has accounted for more than 74 percent of the growth in the number of new pediatric subspecialists being trained nationwide. Bipartisan legislation reauthorizing CHGME through FY 2018 was enacted in 2014, demonstrating the high level of ongoing support among lawmakers for the program.

However, while much has been achieved in strengthening the pediatric workforce, much remains to be done. Since 2000, the national population of children has grown 3 percent, increasing from 72.3 million to 74.2 million today. At the same time, the health care needs of the pediatric population are increasing. The number of children with complex medical conditions is growing at a faster rate than the overall child population, requiring an increased number of specialty care providers.[i]

Unfortunately, funding to train the doctors to serve these children has not kept pace. While children under 18 currently comprise about 23 percent of the U.S. population, only 9 percent of all federal support for graduate medical education is targeted toward training pediatric providers (combining CHGME and Medicare funding for pediatric residents). [ii]

Our nation's commitment to children's health care still lags behind our investment in adults with respect to workforce training. Freestanding children's hospitals, which, as noted, train approximately half of all pediatricians and pediatric specialists, receive almost no federal GME support through Medicare. Furthermore, analysis commissioned by the Children's Hospital Association shows that at current funding levels, the average CHGME payment per full-time equivalent (FTE) resident represents only 45 percent of what Medicare GME provides to support training in adult teaching hospitals.

Strengthening funding for CHGME will help children and their families, including those with rare and complex conditions. Nationwide, serious pediatric workforce shortages persist, most acutely among pediatric subspecialties. The most recent survey data available from children's hospitals shows the following wait times for scheduling appointments due to shortages:

- Developmental pediatrics – Average wait time of 13 weeks
- Endocrinology – Average wait time of 10 weeks
- Neurology – Average wait time of nine weeks
- Pulmonology – Average wait time of eight weeks
- Gastroenterology – Average wait time of five weeks

Localized shortages of pediatric primary care also continue, particularly in certain rural areas.

CHGME has allowed children's hospitals to develop training programs in highly specialized disciplines that target the unique needs of children, including, for example, pediatric surgical oncology, radiation oncology, pediatric pathology and bone marrow transplantation. Only a small number of institutions provide training in some of these areas.[iii] Strong ongoing support is vital to maintain and expand programs focused on these subspecialties, and reductions in funding slow the ability to train providers in areas of need. During a period of reduced CHGME funding earlier in this decade, some hospitals reported that their resident FTE levels, which had been increasing in response to demand, leveled off and declined.

Even with CHGME, children's hospitals incur significant additional costs to subsidize their teaching mission, costs that can be as high as $40 million annually above what they receive from CHGME. These additional costs are particularly difficult to bear given that children's hospitals are typically large Medicaid providers, with more than 50 percent of the average number of days of care covered by Medicaid. Medicaid reimbursement levels in many states remain well below those of private insurance and other government programs, creating another significant fiscal challenge for children's hospitals, particularly as state Medicaid programs have been scaled back significantly in recent years. Without CHGME, hospitals would be at risk of having to cut back training experiences and patient care services impacting children's access to care and the future pediatric workforce.

Furthermore, there are currently no adequate substitutes for CHGME to support training at freestanding children's hospitals. Other potential sources of support, such as Medicaid GME—which has been significantly reduced or eliminated in many states—or competitive grant funding, are not available to many children's hospitals and cannot support training on the scale necessary to meet current and future workforce needs.

The White House's FY 2017 budget proposes converting CHGME to a mandatory funding program, funded at a level of $295 million annually. Children's hospitals applaud the White House for recognizing the need to provide steady, predictable funding for pediatric training. We also are pleased that the President has supported a funding level consistent with that provided by Congress in FY 2016. Children's hospitals look forward to working with Congress on long-term steps to strengthen CHGME. However, in the present term, we believe that it is vital that Congress continue its history of strong bipartisan support of the program through the annual appropriations process.

The CHGME program is critical to protecting gains in pediatric health and ensuring access to care for children nationwide. We recognize that the current budget climate is extraordinarily challenging and that Congress has a responsibility to carefully consider the nation's spending priorities. However, now is the time to take a step forward in pediatric medicine and ensure our children have access to the healthcare services they need.

The Children's Hospital Association, and the children and families we serve, thank you for your past support for this critical program and your leadership in protecting children's health. We respectfully request that the Subcommittee continue its history of bipartisan support for children's health and fund CHGME at its authorized funding level of $300 million in the FY 2017 Labor-HHS appropriations bill.

The Children's Hospital Association advances child health through innovation in the quality, cost and delivery of care. Representing more than 220 children's hospitals, the Association is the voice of children's hospitals nationally. The Association champions public policies that enable hospitals to better serve children and is the premier resource for pediatric data and analytics, driving improved clinical and operational performance of member hospitals. Formed in 2011, Children's Hospital Association brings together the strengths and talents of three organizations: Child Health Corporation of America (CHCA), National Association of Children's Hospitals and Related Institutions (NACHRI) and National Association of Children's Hospitals (N.A.C.H.). The Children's Hospital Association has offices in Washington, DC, and Overland Park, KS.

---

[i] 2014 report, "*Summary of Available Evidence and Methodology for Determining Potential Medicaid Savings from Improving Care Coordination for Medically Complex Children*", prepared for Children's Hospital Association by Dobson DaVanzo & Associates, p. vi.

[ii] Sources: U.S. Census Bureau; 2014 report, "*Comparative Analysis of GME Funding for Children's Hospitals and General Acute Care Teaching Hospitals*", prepared for Children's Hospitals Association by Dobson DaVanzo & Associates.

[iii] Children's Hospital Association fact sheet, *"Percentage of Pediatric Specialists Trained at CHGME Hospitals"* , 2012.

LOWER ELWHA KLALLAM TRIBE

ʔəʔɬx̣ʷə nəxʷsƛaɣəm "Strong People"

2851 Lower Elwha Road
Port Angeles, WA 98363

Phone: 360.452.8471
Fax: 360.452.3428

Written Testimony of
The Honorable Frances G. Charles, Chairwoman
Lower Elwha Klallam Tribe

Submitted to the
House Subcommittee on Labor, Health & Human Services, Education and Related Agencies
On the FY 2017 Budget for a Department-wide Tribal Health and Well-Being Coordinated Budget for the Department of Health and Human Services

April 15, 2016

The Lower Elwha Klallam Tribe supports the President's FY2017 budget proposal for a **"Department-wide Tribal Health and Well-Being Coordinated Budget for the Department of Health and Human Services".** The Affordable Care Act mandated the integration of medical and mental health disciplines at parity and is supported by the FY 2017 proposed budget. This plan would be inclusive of the Substance Abuse and Mental Health Services Administration (SAMHSA), Administration for Children and Families (ACF), Health Resources and Services Administration (HRSA), Centers for Disease Control and Prevention (CDC) and the Indian Health Service (IHS appropriations not included in this Appropriations Subcommittee).

The Lower Elwha Klallam Tribal Health Department operates a multi-disciplinary, ambulatory health department with 9 programs and 81 personnel. We provide services to Lower Elwha Klallam Tribal members, other federally recognized American Indians/Alaskan Natives and people residing in the greater Clallam County area. As a Tribally operated facility, we provide direct patient care services that include medical, dental, mental health, substance abuse, community health, prevention health, integrative services, purchased/referred care and administration. We submit the following appropriations requests:

SUBSTANCE ABUSE AND MENTAL HEALTH SERVICES ADMINISTRATION (SAMHSA):

$30 million - Tribal Behavioral Health Grants

We have a critical need to address the mental health and chemical dependency epidemic in our community. The proposed funding of $30 million, as part of the Generation Indigenous initiative, in the Mental Health ($15 million) and Substance Abuse Prevention ($15 million)

appropriations line items is appreciated but will not have a real impact on the unmet need that increases daily in Indian Country. For the Lower Elwha youth, substance abuse and suicide prevention efforts, we find that there is no budget equity and performance measures value when Tribes have to compete with each other for critically needed funding to address the widespread status of substance abuse and mental health needs of our citizens. Tribal communities have a historical and escalating need that is uncommon to the rest of the population and requires additional resources to effectively treat the overwhelming need. The Lower Elwha Klallam Tribe continues to see the effects of heroin and opioid abuse in all ages at alarming, epidemic rates within Clallam County.

The Lower Elwha Klallam Tribe subsidizes 3rd party funds in attempts to adequately address the treatment and long term needs of our patient population with addiction and behavioral disorders. We realize the need for trauma informed, long-term, American Indian/Alaskan Native treatment facilities to assist those caught in the cycle of addictions. Instead of ignoring the rising heroine and opioid epidemic, we are in support of a budget that will allow the Tribes to facilitate culturally relevant, trauma informed treatment services to our patients so that they can continue their journey of wellness far surpassing the current 30-45 day in-patient treatment process that public insurance does not adequately authorize or reimburse.

In the United States, we do not approach the treatment of other chronic diseases like cancer in this fashion. The Tribe is requesting that the payment and reimbursement model for chemical dependency in-patient and mental health services be critically scrutinized. We urge Congress to fund the integration plan to financially support our efforts in developing a Native best practice treatment and payment system utilizing trauma informed care targeted at our families and communities. There are additional funding areas and payment models that need to be addressed and worked on for the overall health of American Indians and Alaska Native citizens residing throughout the United States.

ADMINISTRATION FOR CHILDREN AND FAMILIES (ACF)

+$20 Million - Increasing Tribal Access to Promoting Safe and Stable Families (PSSF)

The FY 2017 budget requests a $20 million increase in the discretionary PSSF appropriations from the FY 2016 enacted level to increase the capacity of Tribes to administer child welfare services. American Indian and Alaska Native children are disproportionately represented at two times their population in state child welfare systems nationally. Among individual state foster care systems they are overrepresented at as much as 10 times their population rate. This proposal aims to address this disproportionality by investing in Tribal child welfare systems and, in turn, providing culturally appropriate services to Tribal families.

Many Tribes lack infrastructure and stable funding. The Fostering Connections to Success and Increasing Adoptions Act of 2008 allowed Tribes to directly administer Title IV-E programs, but many Tribes need to build their child welfare programs before they are able to consider developing a program meeting the requirements of Title IV-E. With this increase, total funding reserved for formula grants for Tribes would be $31 million, including $22 million discretionary and $9 million mandatory. Also, the FY 2017 budget includes a proposal to improve access to PSSF funding for Tribal grantees by eliminating the current statutory

threshold of $10,000 to receive a grant. It will be replaced with a minimum grant award of $10,000 for all Tribes with approved plans, combined with a hold harmless provision that guarantees that currently funded Tribes receive not less than their current award, so as not to unintentionally undermine the capacity of currently funded grantees. This proposal allows access to critically important funding for preventive services for all Tribes that wish to participate in the program and assures greater stability and predictability in funding year-to-year.

+$2.75 million - Tribal Court Improvement – Tribal Court Improvement Grants assist Tribal courts to:

- Conduct assessments of how Tribal courts handle child welfare proceedings
- Make improvements to court processes to provide for the safety, permanency, and well-being of children as set forth in the Adoption and Safe Families Act (ASFA) and increase and improve engagement of the entire family in court processes relating to child welfare, family preservation, family reunification, and adoption
- Ensure children's safety, permanency, and well-being needs are met in a timely and complete manner (through better collection and analysis of data)
- Provide training for judges, attorneys, and legal personnel in child welfare cases

This increase will allow ACF to fund a total of 25 Tribal court improvement grants. The expansion of the Tribal Court Improvement Program would continue to strengthen the Tribal court's capacity to exercise jurisdiction in Indian Child Welfare Act cases and to adjudicate child welfare cases in Tribal court.

CLOSING

There are additional funding areas and payment models that need to be addressed and worked on for the overall health of American Indians and Alaska Native citizens residing throughout the United States. The support of the Congress and the Administration with these efforts is greatly appreciated.

Testimony from Emily Sheketoff, the American Library Association, submitted to the House Appropriations Subcommittee on Labor, Health and Human Services and Education, and Related Agencies. Testimony supports funding for the Library Services and Technology Act (LSTA) and $27 million for Innovative Approaches to Literacy (IAL).

The American Library Association (ALA) is the oldest and largest library association in the world, with more than 58,000 members in academic, public, school, government, and special libraries. Our mission is to provide leadership for the development, promotion and improvement of library and information services and the profession of librarianship in order to enhance learning and ensure access to information for all. On behalf of ALA, I want to thank the Labor, Health and Human Services, Education, and Related Agencies Subcommittee for the opportunity to provide comments in support of two important, long-standing, cost-effective and highly successful programs that assist and empower students, families, businesses, veterans, families with differently-abled members, and many others.

Specifically, we urge the Subcommittee to include in its appropriations bill $186.6 million for the Library Services and Technology Act (LSTA) under the Institute of Museum and Library Services (IMLS) and $27 million for the Innovative Approaches to Literacy (IAL) program under the Department of Education (DOE). Both LSTA and IAL are authorized by Congress. Below are just a few examples, among hundreds, of the profound, day-to-day impact that Congress' modest but essential investment LSTA produces for Americans everywhere every day:

- One of the most fundamental roles of the public library is to help young children become future readers. To aid in this effort, the Missouri State Library leveraged its LSTA grant to embark on a statewide initiative called *Racing to Read.* The *Racing to Read* program, developed by the Springfield-Greene Public Library in Springfield features fun activities that help children get ready to learn to read by focusing on five basic skills: telling stories, talking and reading, singing and rhyming, playing with letters, and loving books. These activities are easily incorporated into a library's preschool story times, and are shared with parents and caregivers for use at home, at day care centers and with partner agencies.

- When returning soldiers in Modesto, CA, needed help readjusting to [reentering] the civilian world, the Stanislaus Public Library was able to step in and provide the transitional assistance they needed. The library used its LSTA grant to create a program educating veterans about the array of services and benefits available to them and their families. The library also has assisted vets with their online education and employment needs. The Stanislaus Public Library is one of 38 California public libraries offering a Veterans Resource Center, all of them made possible in part by LSTA funding.

- New businesses in Kings Mountain, NC struggled to survive yet were closing at a high rate. Local businesses in this rural community needed resources to more effectively compete. The Mauney Memorial Library used its LSTA grant to create the Downtown Kings Mountain Small Business Success Project, hiring a business librarian all of whose

time was dedicated to assisting local businesses in development of a successful 21st century market online presence. The Success Project's business librarian worked with businesses on learning to: develop business plans, manage social media, analyze marketing and other data, conduct market research, plan more effectively, and to improve safety and security audits. The librarian also helped individual businesses to develop professional caliber websites.

Without LSTA funding, these and many other specialized programs targeted to the needs of their communities across the country likely will be entirely eliminated, not merely scaled back. In most instances, LSTA funding (and its required but smaller state match) allows libraries to create new programs for their patrons, like those described above. Without LSTA underwriting, however, tight state and local budgets mean that libraries simply will not have the resources to institute and keep these programs, which are so valuable to so many Americans.

The beneficiaries of the many services that libraries offer are by no means limited, however, to the targeted participants in special programs like the ones just described, Mr. Chairman. Rather, America's nearly 17,000 public libraries serve an astonishing 4 million people daily in communities of every size and in every corner of the country. In addition to the kinds of veterans outreach and business-building assistance described above, libraries routinely also offer Americans from every walk of life ready and free access to all types of information, career and workforce skills training, digital and print literacy instruction, job searching databases, resume workshops, summer reading projects, creative programming for children, best practices training for local librarians, access to teleconferencing facilities, and 3D printers, and so much more. Indeed, according to an ALA report, more than 92 percent of public libraries offer services that help patrons complete job applications, create resumes, and access job databases and research. Libraries also provide resources and specialized collections for small businesses, which help them create business plans, develop new growth strategies, and research target markets.

Perhaps most critically, however, every day thousands of libraries across the country also provide no-fee public access to computers and the internet in some of our most distressed communities, both rural and urban. For the approximately 19 million Americans who cannot afford broadband at home, or who live in rural areas where the infrastructure does not support home broadband, libraries are an indispensable access point to the internet. According to a recent ALA report, 65 percent of all libraries nationwide are the only provider of free internet access in their communities. In rural areas, public libraries are even more critical, with 73 percent serving as their community's only free internet provider. Increasingly, the internet is the only means by which an individual can research job opportunities, take their GED, apply for a job, or submit government forms, such as tax filings or benefit claims. Many individuals could not even submit comments to this Subcommittee without access to broadband at their local library. LSTA funding often is what makes these services possible.[1]

[1] LSTA also funds: the Native American and Native Hawaiian Library Services program to support improved access to library services for those populations; National Leadership Grants to support activities of national significance that enhance the quality of library services nationwide, and provide pilots for coordination between libraries; and the Laura Bush 21st Century Librarians program, used to help develop and promote the next generation of librarians.

The bulk of LSTA funds are distributed to each state through IMLS according to a population-based grant formula. Each state must match the federal funds received and determines for itself how to best allocate its LSTA awards, As the examples above merely hint at, libraries have used LSTA funding myriad diverse and innovative programs that profoundly touch and better the lives of tens of millions of Americans in every state in the nation. LSTA is truly a local decision-making success story.

During this time of increased and increasing demand, many libraries are under severe budget pressure. The support they receive through the LSTA, the primary source of annual funding for libraries in the federal budget, is thus critical to meeting the needs of Americans everywhere and, in so doing, building our economy one job and one community at a time.

Accordingly, Mr. Chairman, ALA asks that you and the Committee provide $186.6 million for LSTA in FY 2017 to ensure that Americans of all ages continue to have access to the life- sustaining, -affirming and -expanding resources that their trusted local libraries provide. ALA respectfully submits, Mr. Chairman, that there can be few, if any, more democratic, cost-effective and impactful uses of federal dollars than LSTA in the entirety of the federal budget.

Libraries, of course, also have tremendous impact upon the nation's children, especially our most needy, opening their eyes and minds to books and information of all kinds that help them gain and enhance literacy skills. Surveys show that many of our nation's children living in poverty have no books at home. These children depend on their local libraries' story-time and summer reading programs to help them prepare to learn in school and to succeed.

In addition to supporting LSTA, ALA also asks that you maintain FY 2016's modest, but critical, federal investment of $27 million in the Innovative Approaches to Literacy (IAL) program. IAL provides competitive awards to school libraries and national not-for-profit organizations (including partnerships that reach families outside of local educational agencies) to put books into the hands of children and their families in high-need communities. Providing books and childhood literacy activities to such children is crucial to their learning to read, which is crucial to their – and the nation's – economic futures. The program also supports parental engagement in their children's' reading life, and focuses on promoting student literacy from birth through high school. IAL was authorized under the Every Student Succeeds Act of 2015.

Congress first recognized the importance of this program in FY 2012 when $28.6 million was appropriated for early literacy support. In 2012, the U.S. Department of Education awarded two-year IAL grants to 46 nonprofit organizations and school districts in 21 states and the District of Columbia. In 2014, the Department made 32 new awards to national non-profits and school libraries. As with LSTA funds, school libraries and others are doing remarkable, valuable work with IAL support, as these brief examples reveal:

- The Waukegan Community Unit School District in Illinois sought to improve literacy achievement in this lower income community with a high percentage of families where English is the second language. The school's library used an IAL grant to implement its "Ladders to Literacy" program, and innovative print and e-book based curriculum that

also provided targeted literacy coaching and development for teachers. It measurably succeeded in improving participants' reading achievement.

- In the Milwaukee Public Schools, an IAL grant supported a project by its Focus on Literacy Foundation (nicknamed "FLF"). FLF sought to improve kindergarten through 4th grade literacy through innovative uses of technology, encouraging family reading-involvement opportunities, and the distribution of books to students with which they could expand their own home libraries. FLF was implemented at four low-achieving schools serving economically disadvantaged children who often had no books at home at all.

Studies show that strong literacy skills and year-round access to books is a critical first-step towards literacy and life-long learning. For American families living in poverty, access to reading materials is severely limited. These children have fewer books in their homes than their peers, which hinders their ability to prepare for school and to stay on track.

Congress has taken an important step in supporting the needs of disadvantaged students by providing IAL funding for book distribution, early literacy services, and effective school library programs. We urge the Subcommittee and full Committee to continue this important work by maintaining a $27 million investment in IAL in the FY 2017 Labor, Health and Human Services, Education, and Related Agencies bill.

ALA urges and appreciates the Subcommittee's continued strong support of LSTA and IAL, Mr. Chairman. Thank you for your commitment to sustaining and strengthening our communities and our nation by sustaining and strengthening America's libraries.

Expanding Opportunities for Veterans
and All Paralyzed Americans

April 15, 2016

House Committee on Appropriations Subcommittee on
Labor, Health and Human Services,
Education, and Related Agencies
Committee on Appropriations
United States House of Representatives
Washington, DC 20515

I am Alexandra Bennewith, Vice President, Government Relations with United Spinal Association and I am writing to support the National Council on Independent Living's request for Congress to reaffirm your commitment to the more than 57 million Americans disabilities by increasing funding in the HHS appropriations for Centers for Independent Living (CILs). I am asking that you increase funding by $200 million, for a total of $301 million for the Independent Living line item in FY 2017.

United Spinal Association is the largest disability-led national non-profit organization founded by paralyzed veterans in 1946 and has since provided service programs and advocacy to improve the quality of life of those across the life span living with spinal cord injuries and disorders (SCI/D) such as multiple sclerosis, amyotrophic lateral sclerosis (ALS), post-polio syndrome and spina bifida. United Spinal represents over one million individuals with spinal cord injuries and disorders, 50 chapters, 103 rehabilitation hospital members and close to 200 support groups nationwide. Throughout its history, United Spinal Association has devoted its energies, talents and programs to improving the quality of life for these Americans and for advancing their independence. United Spinal Association is also a VA-recognized veterans service organization (VSO) serving veterans with disabilities of all kinds.

CILs are cross-disability, non-residential, community-based, nonprofit organizations that are designed and operated by individuals with disabilities. CILs are unique in that they are directly governed and staffed by people with all types of disabilities, including people with mental, physical, sensory, cognitive, and developmental disabilities. Each of the 365 federally funded centers provides five core services: information and referral, individual and systems advocacy, peer support, independent living skills training, and transition services, which were added with the passage of the Workforce Innovation and Opportunity Act (WIOA). From 2012-2014, CILs provided the core services to nearly 5 million people with disabilities, and provided additional services such as housing assistance, transportation, personal care attendants, and employment services to hundreds of thousands of individuals. During this same period, prior to transition being added as a core service, CILs transitioned 13,030 people with disabilities from nursing homes and other institutions into the community.

Transition services were added as a fifth core service with the 2014 reauthorization of the Rehabilitation Act within the Workforce Innovation and Opportunity Act. Transition services include the transition of individuals with significant disabilities from nursing homes and other

institutions to home and community-based residences with appropriate supports and services, assistance to individuals with significant disabilities at risk of entering institutions to remain in the community, and the transition of youth with significant disabilities to postsecondary life. This core service is vital to achieving full participation for people with disabilities.

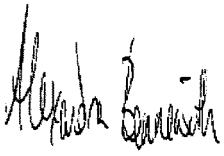
Every day, CILs are fighting to ensure that people with disabilities gain and maintain control over our own lives. We know that this cannot occur when people reside in institutional settings. Opponents of deinstitutionalization say that allowing people with disabilities to live in the community will result in harm. We know that the 13,030 people with disabilities who CILs successfully transitioned out of nursing homes and institutions from 2012-2014 prove otherwise. Additionally, when services are delivered in an individual's home, the result is a tremendous cost savings to Medicaid, Medicare, and states. Community-based services enable people with disabilities to become less reliant on long-term government supports, and they are significantly less expensive than nursing home placements. We are grateful that Congress demonstrated their understanding and support for community-based services when WIOA was passed and transition was added as a fifth core service.

Since transition services were added as a core service, the need for funding is critical. Moreover, CILs need additional funding to restore the devastating cuts to the Independent Living program, make up for inflation costs, and address the increased demand for independent living services. In 2016, the Independent Living Program is receiving $2.5 million less in funding than it was in 2010. It is simply not possible to meet the increasing demand for services and effectively provide transition services without additional funding. Increased funding should be reinvested from the billions currently spent to keep people with disabilities in costly Medicaid nursing homes and institutions and out of mainstream society.

Centers for Independent Living play a crucial role in the lives of people with disabilities, and work tirelessly to ensure that people with disabilities have a real choice in where and how they live, work, and participate in the community. Additionally, CILs are an excellent service and a bargain for America, keeping people engaged with their communities and saving taxpayer money. NCIL is dedicated to increasing the availability of the invaluable and extremely cost-effective services CILs provide, and they have submitted written testimony with a similar request. I strongly support NCIL's testimony.

If you have any questions, please contact me at (202) 556-2076 or abennewith@unitedspinal.org.

Sincerely,



Alexandra Bennewith, MPA
Vice President, Government Relations

Yasmina Vinci
Executive Director, National Head Start Association
Subcommittee on Labor, Health & Human Services and Education and Related Agencies
Department of Health and Human Services
Head Start and Early Head Start

April 15, 2016

Dear Chairman Cole, Ranking Member DeLauro, and Members of the Committee,

On behalf of the National Head Start Association (NHSA), thank you for the opportunity to submit written testimony regarding funding for Head Start and Early Head Start in Fiscal Year 2017. For more than 50 years, Head Start has created opportunities for disadvantaged children and families to succeed by providing the highest quality early childhood education, including health, nutrition, parent engagement, family support and child development services. NHSA is grateful for the Subcommittee's tradition of strong bipartisan support for early childhood education. In Fiscal Year 2017, NHSA respectfully requests the Subcommittee allocate **$9,601,724,000** for Head Start and Early Head Start. This amount is in line with the President's FY2017 request and represents a $434,000,000 increase over FY16 enacted levels.

Head Start and Early Head Start directors nationwide remain appreciative of your leadership in preventing the return of sequestration in Fiscal Years 2016 and 2017, as well as providing a significant increase in funding for Head Start in FY16. The FY16 funds will expand infant-toddler access, strengthen quality through increased duration of services, and help enable Head Start programs to keep pace with rapidly rising operating costs. They will also allow the Head Start field to prepare for and begin implementation of new Head Start Program Performance Standards, which the Administration proposed in June 2015 and are expected to be made final in

2016. The entire Head Start field sincerely appreciates the additional investment and commitment Congress continues to make in our nation's future by supporting youth and families in our most underserved communities.

NHSA recognizes the restrictions and challenges of the FY17 budget and the top-line discretionary spending limits. However, as we strongly believe in continuous quality improvement and are intent on implementing new Head Start Program Performance Standards with minimal impact to the number of children and families served nationwide, we strongly encourage you to consider the funding needs and priorities necessary to strengthen and grow Head Start, as identified by the Head Start community. An investment of $9.6 billion will allow Head Start centers to continue services to the nearly one million children and their families from birth through age five currently enrolled in Head Start and Early Head Start, as well as continue to strengthen quality through the expanded duration of services, improved teacher retention, and direct quality improvement funds as identified in the 2007 Head Start Act.

NHSA urges the Subcommittee to continue to build on last year's investments. Should the Committee have the flexibility to invest in Head Start programs above the FY16 enacted level, we offer the following prioritized funding recommendations:

Supporting Quality Workforce Retention: Within the sum provided, NHSA recommends **$141,629,000** be allocated for Workforce Investments through a cost-of-living adjustment. Nearly every Head Start provider struggles to retain quality staff due to non-competitive salaries. Furthermore, high staff turnover rates directly impact quality of services to young children.

Investing in workforce quality is the most important and pressing need for programs across the country. Recent Program Information Report (PIR) data strongly suggest that when Head Start grantees receive a Workforce Investment, there is less teacher turnover. For example, in the 2008-2009 school year, when there was not a Workforce Investment 26.5 percent of teachers who left Head Start cited salary as the main reason for their departure. The next two years, when Congress made a significant Workforce Investment through the Recovery Act and annual appropriations, that number dropped to 20.9 percent in 2009-2010 and 19.3 percent in 2010-2011. The next year, 2011-2012, turnover increased back to 26.2 percent when there was not a Workforce Investment. Teacher turnover has a direct impact on the quality and stability of programs and we strongly encourage Congress to do everything possible to help mitigate this growing concern. [1]

Supporting Duration Expansion: Within the overall sum, NHSA recommends **$292,000,000** be allocated for flexible Quality Improvement funding (QIF), without restrictions, to support the preparation and implementation of the new Head Start Performance Standards. Authorized in the 2007 Head Start Act, QIF may be used for increasing duration of instruction time, staff training, improving community-wide planning and classroom environments, strengthening transportation safety, and increasing hours of program operation. The QIF offers local centers flexibility to prepare their communities for duration expansion and other policies to strengthen quality as part of the new standards.

NHSA largely concurs with the goals outlined in the proposed standards of ensuring continuous quality improvement, strengthening evidence-based practices, and expanding duration of Head

[1] U.S. Department of Health and Human Services. (2015, November). 2008-2015 Head Start Program Information Reports.

Start programming. However, not every Head Start center and community is ready to immediately expand their programs – some centers require additional community-wide planning, classroom improvements, and safer transportation systems before they can increase the hours of services. By allocating funding through the Quality Improvement Fund, Congress will allow those Head Start centers who are fully prepared to expand services immediately, while also providing sufficient flexibility to assist those centers that require additional preparation before they can expand with quality. An increase in the Quality Improvement Fund will ensure that duration expansion does not come at the expense of the number of children and families served.

Head Start Returns the Public's Investment: Given the constrained fiscal environment in FY17, NHSA recognizes the need to prioritize programs with demonstrable returns on the investment in public dollars. Studies have proven that for every one dollar invested in a Head Start child, society earns at least seven dollars back through increased earnings, employment, and family stability;[2] as well as decreased welfare dependency,[3] health care costs,[4] crime costs,[5] grade retention,[6] and special education.[7] The latest science in brain development shows that the ages of zero to five are the most critical in a child's life. Head Start and Early Head Start ensure that children from the most disadvantaged communities receive the nurturing, engaging, and healthy education necessary for an equal opportunity to succeed later in life. In 2014-2015, there

[2]Benefits and Costs of Head Start. *Social Policy Report*. 21 (3: 4); Deming, D. (2009). Early childhood intervention and life-cycle skill development: Evidence from Head Start. *American Economic Journal: Applied Economics*, 1(3): 111-134; Meier, J. (2003, June 20). Interim Report. Kindergarten Readiness Study: Head Start Success. Preschool Service Department, San Bernardino County, California; Deming, D. (2009, July). Early childhood intervention and life-cycle skill development: Evidence from Head Start, p. 112.

[3]Meier, J. (2003, June 20). Kindergarten Readiness Study: Head Start Success. Interim Report. Preschool Services Department of San Bernardino County.

[4] Friswold, D. (2006, February). Head Start participation and childhood obesity. Vanderbilt University Working Paper No. 06-WG01; Currie, J. and Thomas, D. (1995, June). Does Head Start Make a Difference? *The American Economic Review, 85* (3): 360; Anderson, K.H., Foster, J.E., & Frisvold, D.E. (2009). Investing in health: The long-term impact of Head Start on smoking. *Economic Inquiry*, 48 (3), 587-602.

[5]Americans too high: Pew study; Garces, E., Thomas, D. and Currie, J. (2002, September). Longer-term effects of Head Start. *American Economic Review*, 92 (4): 999-1012.

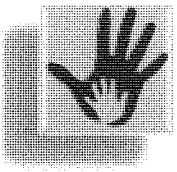
[6]Over Head Start: What the Research Shows.; Garces, E., Thomas, D. and Currie, J. (2002, September). Longer-Term Effects of Head Start. *American Economic Review, 92* (4): 999-1012.

[7] NHSA Public Policy and Research Department analysis of data from a Montgomery County Public Schools evaluation. See Zhao, H. & Modarresi, S. (2010, April). *Evaluating lasting effects of full-day prekindergarten program on school readiness, academic performance, and special education services*. Office of Shared Accountability, Montgomery County Public Schools.

were **4,770,452** children in poverty under age five.[8] Of those, only **41%** of three and four year olds had access to Head Start. And only **4%** of children under age three had access to Early Head Start. Investments in Head Start are investments in the success of our nation's future generations and, while we have made significant strides the past several years, we could do more.

Again, the Head Start community understands the pressure the Subcommittee faces in Fiscal Year 2017 and we are grateful for the commitment shown by Congress and the President to keep early learning, and Head Start in particular, a priority. We urge the Subcommittee to build on investments to Head Start and Early Head Start in FY2017 in order to increase workforce retention, provide continuous quality improvement, and expand duration or services. Thank you for your time and consideration.

[8] Kids Count Data Book. (2015). Children in poverty by age group. The Annie E. Casey Foundation. Retrieved from http://datacenter.kidscount.org/data



Children's
Environmental
Health
Network

110 Maryland Avenue NE, Suite 402
Washington, DC 20002
202.543.4033
www.cehn.org
cehn@cehn.org

April 15, 2016

Testimony submitted by Nsedu Obot Witherspoon, M.P.H., Executive Director of the Children's Environmental Health Network before the Subcommittee on Labor, Health & Human Services, Education & Related Agencies
United States House Committee on Appropriations

Regarding FY2017 Appropriations for children's environmental health programs

The Children's Environmental Health Network (CEHN or the Network) is pleased to have this opportunity to submit testimony on FY 2017 appropriations for the following programs and activities that safeguard the health and future of all of our children:

- Centers for Disease Control and Prevention ($7.8 billion), especially the National Center for Environmental Health ($236.899 million) and its programs, including:
    - Healthy Homes and Lead Poisoning Prevention Program ($35 million)
    - National Asthma Control Program ($30.596 million)
    - National Environmental Public Health Tracking Program ($50 million)
- National Institute of Environmental Health Sciences (NIEHS) ($717.7 million), to continue support of efforts focused on children
- Pediatric Environmental Health Specialty Units (PEHSUs)

The Children's Environmental Health Network (CEHN) was created more than 20 years ago by concerned pediatricians and researchers with a goal of protecting the developing child from environmental health hazards and to promote a healthy environment. Today's children are facing the distressing possibility that they may be the first generation to see a shorter life expectancy

than their parents due to poor health. Key contributors to this trend are obesity, asthma, learning disabilities, and autism. For all of these conditions, the child's environment plays a role in causing, contributing to or mitigating these chronic conditions. The estimated costs of environmental disease in children (such as lead poisoning, childhood cancer, and asthma) were $76.6 billion in 2008.[1] Investments in programs that protect and promote children's health will be repaid by healthier children with brighter futures.

Additionally, protecting our children -- those born as well as those yet to be born -- from environmental hazards is a national security issue. When we protect children from harmful chemicals in their environment, we help to assure that they will reach their full potential. American competiveness depends on having healthy, educated children who grow up to be healthy productive adults. It is vital that the Federal programs and activities that protect children from environmental hazards receive adequate resources. We strongly urge the Committee to support and expand children's environmental health programs. Key programs in your jurisdiction deserving your support include:

Centers for Disease Control and Prevention (CDC)

As the nation's leader in public health promotion and disease prevention, the CDC should receive top priority in federal funding. CDC continues to be faced with unprecedented challenges and responsibilities. CEHN applauds your support for CDC in past years and urges you to support a funding level of $7.8 billion for CDC's core programs in FY 2017.

The **National Center for Environmental Health (NCEH)** is particularly important in protecting the environmental health of young children. This is especially evident as seen by the

[1] Trasande, Liu Y. "Reducing The Staggering Costs Of Environmental Disease In Children, Estimated At $76.6 Billion In 2008, *Health Affairs*. No. (2011): doi: 10.1377/hlthaff.2010.1239

recent crisis in Flint, Michigan, were the critical role that core environmental health services must play in protecting our families and communities is front and center. Current research is uncovering the extensive role that environment plays in human health and development. As a result, NCEH partners with public health agencies and a wide range of other organizations to bring their expertise and support to an expanding scope of environmental-human health challenges. NCEH's programs are key national assets. Yet in recent years, NCEH funding has been drastically cut. We urge the Subcommittee to provide $236.899 million to NCEH to support these critical programs.

Support critically underfunded childhood lead poisoning prevention activities by funding the CDC **Healthy Homes and Lead Poisoning Prevention Program** at $35 million. This funding level will provide grants in all fifty states for surveillance to determine the extent of childhood lead poisoning, as well as educate the public and health care providers about lead poisoning, and ensure that lead-exposed children received needed medical and environmental follow-up services. There is no safe level of lead exposure and lead damage can be permanent and irreversible leading to a myriad of academic and behavioral problems in school, failure to graduate and a host of other health impairments later in life. Today over 500,000 children are exposed to unacceptably high levels of lead

NCEH's **National Asthma Control Program** not only has greatly increased data collection about this rampant epidemic but it also encourages states to use evidence-based approaches to reduce costs and improve outcomes for people living with asthma. Asthma is an epidemic in the U.S., affecting 10% of our nation's children. We urge the Committee to fund this vital program at $30.596 million in FY 2017.

Public health officials need integrated health and environmental data so that they can protect the public's health. The CDC's **National Environmental Public Health Tracking Program** helps to track environmental hazards and the diseases they may cause and to coordinate and integrate local, state and Federal health agencies' collection of critical health and environmental data. Participation in the tracking network development will decline under further cuts and erase the progress we have made across the country to better link data with public health action.

National Institute of Environmental Health Science (NIEHS)

NIEHS is the leading institute conducting research to understand how the environment influences human health. Unlike other NIH Institutes focused on one disease or one body system, NIEHS is charged with all diseases, all human health and body systems, as they are affected by the environment – a vital and monumental charge. NIEHS plays a critical role in our efforts to understand how to protect children, whether it is identifying and understanding the immediate impact of chemical substances or understanding childhood exposures that may not affect health until decades later. CEHN recommends that $732.3 million be provided for NIEHS' FY 2017 budget.

Children are uniquely vulnerable to harmful substances in their environment, and the NIEHS plays a critical role in uncovering the connections between environmental exposures and children's health. Today's pediatric health challenges are chronic conditions such as obesity, asthma, learning disabilities, and autism; and for all of these health challenges, environment plays a role in cause, prevention, or mitigation. Recent NIEHS funded studies have shown that exposure to traffic-related air pollution (nitrogen dioxide, PM2.5, and PM10) during pregnancy and the first year of life is associated with the development of autism. Additional research on likely biological pathways is needed to determine whether these associations are causal.

Pediatric Environmental Health Specialty Units

Pediatric Environmental Health Specialty Units (PEHSUs) form a valuable resource network for parents and clinicians around the nation. They are funded jointly by the Agency for Toxic Substances and Disease Registry (ATSDR) and the EPA with a very modest budget. PEHSU professionals provide medical consultation to health care professionals from individual cases of exposure to advice regarding large-scale community issues. PEHSUs also provide information and resources to school, child care, health and medical, and community groups and help inform policymakers by providing data and background on local or regional environmental health issues and implications for specific populations or areas. We urge the Subcommittee to fully fund ATSDR's portion of this program in FY 2017.

Thank you for the opportunity to submit this testimony.

Testimony Prepared by Carly Finkle, Advocacy Manager at The Food Bank of Contra Costa and Solano for the United State House Committee on Labor, Health and Human Services, and Education, and Related Agencies addressed to the Department of Health and Human Services

April 15, 2015

The Food Bank of Contra Costa and Solano is part of a nationwide coalition, the Food is Medicine Coalition, of over 80 food and nutrition services providers, affiliates and their supporters across the country that provide food and nutrition services to people living with HIV/AIDS (PWH) and other chronic illnesses. Through the Food Bank of Contra Costa's Extra Helpings program, we provide 30 pounds of nutritious food at no cost to over one hundred people living with HIV. Collectively, the Food is Medicine Coalition is committed to increasing awareness of the essential role that food and nutrition services (FNS) play in successfully treating HIV/AIDS and to expanding access to this indispensable intervention for people living with other severe illnesses.

1.) Why Food and Nutrition Services (FNS) Matter for PWH

While adequate food and nutrition are basic to maintaining health for all persons, good nutrition is crucial for the management of HIV infection. Proper nutrition is needed to increase absorption of medication, reduce side effects, and maintain healthy body weight. Research has identified the virus as an independent risk factor for cardiovascular, liver and kidney disease, cancer, osteoporosis and stroke. Several HIV medications can cause nausea and vomiting and some can affect lab results that test lipids and kidney and liver function. These compounding health effects, caused by the virus and its medications, reinforce the important role a nutrient-rich diet plays in a patient's overall care plan. In addition, providing food and nutrition services can serve to facilitate access and engagement with medical care, especially among vulnerable populations.

The Food and Nutrition Services category within the Ryan White Program includes medical nutritional therapy (MNT) and food and nutrition services (FNS). MNT covers nutritional diagnostic, therapy, and counseling services focused on prevention, delay or management of diseases and conditions, and involves an in-depth assessment, periodic reassessment and intervention provided by a licensed, Registered Dietitian Nutritionist (RDN) outside of a primary care visit. The range of FNS provided through the Ryan White program complements the needs of PWH at any stage of their illness. For those who are most mobile, there are congregate meals, walk-in food pantries and voucher programs. For those whose disease has progressed, home-delivered meals and home-delivered grocery bags complement their medical treatment.

Since 2006, HRSA has included MNT and FNS, provided under the guidance of RDNs, as a clinically effective **core medical service** in the Ryan White Program. These services play a critical role in ensuring that PWH enter and continue in primary medical care, adhere to their medications, and ultimately achieve viral suppression.

2.) FNS as a Care Completion Service Unique to Ryan White

Social and economic interventions, most often in the form of care completion service like food and nutrition services, are fundamental to making health care work for PWH. Support services for PWH are not covered in any comprehensive way by Medicaid or other public insurance initiatives that have been expanded by the Affordable Care Act. As the HIV epidemic in the United States increasingly impacts low-income individuals, support services help stabilize individuals living with or at risk of HIV. When needs are met, and life's emergencies are held at bay, PWH are poised to remain connected to care and treatment.

3.) Access to FNS and the Triple Aim

Access to appropriate food and nutrition services (FNS) are increasingly recognized as key to accomplishing the triple aim of national healthcare reform for PWH.

Better Health Outcomes
When clients get effective FNS and become food secure, they then keep scheduled primary care visits, score higher on health functioning, are at lower risk for inpatient hospital stays and are more likely to take their medicines[i]. Studies show both the health benefits of access to MNT and/or nutrition counseling for people with HIV infections[ii] and the resulting decreases in their healthcare costs. Compare these outcomes to PWH who are food insecure, who have:

- Lower CD4 counts & lower likelihoods of having undetectable viral loads[iii]
- More ER visits[iv] & increased morbidity and mortality[v]
- More missed primary care appointments & reduced use of antiretroviral therapy[vi].

Lower Healthcare Costs
Millions of dollars in healthcare expenditures are saved through the provision of FNS to PWH. A recent study comparing participants in a medically-tailored FNS program vs. a control group within a local managed care organization found that average monthly healthcare costs for PWH fell 80% in first three months after receiving FNS[vii]. If hospitalized, nourished clients' costs were 30% lower, their hospital length of stay was cut by 37% and they were 20% more likely to be able to be discharged to their homes rather than a more expensive institution[viii]. Furthermore, FNS are a very inexpensive intervention. For each day in a hospital saved, you can feed a person a medically-tailored diet for half a year.

Improved Patient Satisfaction
Studies show nutrition counseling improves quality of life[ix]. Members overwhelmingly report that our services help them live more independently, eat more nutritiously and manage their medical treatment more effectively.

4.) FNS and the National HIV/AIDS Strategy (NHAS)
Access to FNS for PWH is fundamental to fulfilling the goals of the NHAS.

- **NHAS Goal: Reducing new HIV infections:** PWH who are food insecure are less likely to have undetectable viral loads in a statistically significant way. Undetectable viral loads prevent transmission 96% of the time[x], thus, FNS is key to prevention[xi].
- **NHAS Goal: Increasing access to care and improving health outcomes for people living with HIV:** PWH who receive effective FNS are more likely to keep scheduled primary care visits, score higher on health functioning, are at lower risk for inpatient hospital stays and are more likely to take their medicines[xii].
- **NHAS Goal: Reducing HIV-related disparities and health inequities:** By providing FNS to PWH who are in need largely because of poverty, we improve health outcomes, thereby reducing health disparities[xiii].
- **NHAS Goal: Achieving a more coordinated national response to the HIV epidemic:** There remains a tremendous variation by state in coverage of food and nutrition services both inside and outside of Ryan White, making support for Ryan White HIV Program all the more needed. Ultimately, if we are going to achieve a more coordinated national response to the HIV epidemic and our quest to reduce healthcare spending nationwide, FNS must be included in all healthcare reform efforts, including Ryan White and the ACA.

Conclusion
We are deeply aware of the difficult decisions that face the members of the Committee in the current fiscal environment. Yet, research shows that investment in FNS, with the great return in prevention and retention in HIV care, are vital to lowering the number of new infections in the domestic HIV epidemic and ultimately reducing healthcare costs and preserving healthcare resources for the future. A client's diet can literally have life and death consequences. When people are severely ill, good nutrition is one of the first things to deteriorate, making recovery and stabilization that much harder, if not impossible. Early and reliable access to medically-

appropriate FNS helps PWH live healthy and productive lives, produces better overall health outcomes and reduces health care costs.

Along with our colleagues, we appreciate the opportunity to offer this testimony regarding the FY 2017 Appropriations process. We are also pleased to offer our assistance and expertise, including information from our Research Library.

Sincerely,

Carly Finkle
Advocacy Manager
The Food Bank of Contra Costa and Solano
4010 Nelson Ave, Concord, CA 94904
(925) 849-8361
cfinkle@foodbankccs.org

---

[i] Aidala A, Yomogida M, Vardy Y & the Food & Nutrition Study Team. Food and Nutrition Services, HIV Medical Care, and Health Outcomes. New York State Department of Health: Resources for Ending the Epidemic, 2014. Available at https://www.health.ny.gov/diseases/aids/ending_the_epidemic/docs/key_resources/housing_and_supportive_services/chain_factsheet3.pdf

[ii] Academy of Nutrition and Dietetics (formerly American Dietetic Association). HIV/AIDS Nutrition Evidence Analysis Project at http://www.adaevidencelibrary.com/conclusion.cfm?conclusion_statement_id=250707 Accessed 29 July 2012.

[iii] Aidala A., Yomogida M., and the HIV Food & Nutrition Study Team (2011);
Singe AW,Weiser SD, McCoy, SI. Does Food Insecurity Undermine Adherence to Antiretroviral Therapy? A Systematic Review. AIDS Behav (2015) 19:1510–1526.

[iv] Ibid.

[v] Anema A, Chan K, Yip B, Weiser S, Montaner JSG, Hogg RS. Impact of food insecurity on survival among HIV-positive injection drug users receiving antiretroviral therapy in a Canadian cohort. 141st APHA Annual Meeting, Nov. 2-6, 2013. Boston, MA. Abstract #: 290277

[vi] Aidala A., Yomogida M., and the HIV Food & Nutrition Study Team (2011).

[vii] Gurvey J, Rand K, Daugherty S, Dinger C, Schmeling J, Laverty N. Examining Health Care Costs Among MANNA Clients and a Comparison Group. J Prim Care Community Health. (2013) 4:311-317

[viii] Ibid.

[ix] Rabeneck L, Palmer A, Knowles JB, Seidehamel RJ, Harris CL, Merkel KL, Risser JMH, Akrabawi SS. A randomized controlled trial evaluating nutrition counseling with or without oral supplementation in malnourished HIV-infected patients. J Am Diet Assoc. (1998) 98: 434-438;Schwenk A, Steuck H, Kremer G. Oral supplements as adjunctive treatment to nutritional counseling in malnourished HIV-infected patients: randomized controlled trial. Clinical Nutrition (1999) 18(6): 371-374.

[x] M. S. Cohen *et al.*, Prevention of HIV-1 Infection with Early Antiretroviral Therapy. N. Engl. J. Med.(2011) 365, 493-505 . HPTN 052

[xi] Palar K, Laraia B, Tsai A, Weiser SD Food insecurity is associated with sexually transmitted infections and HIV serostatus among low income adults in the National Health and Nutrition Examination Survey (NHANES) (1999-2010). Presented at the American Public Health Association 141st Annual Meeting, Boston, MA, November 5, 2013.

[xii] Aidala A, Yomogida M, Vardy Y & the Food & Nutrition Study Team. Food and Nutrition Serviees, HIV Medical Care, and Health Outcomes. New York State Department of Health: Resourees for Ending the Epidemic, 2014. Available at

xiii Weiser SD, Frongillo EA, Ragland K, Hogg RS, Riley ED, Bangsberg DR. Food insecurity is associated with incomplete HIV RNA suppression among homeless and marginally housed HIV-infected individuals in San Francisco. J Gen Intern Med. (2009) 24(1):14-20.

FAMILY & COMMUNITY SERVICE
of Delaware County

Administrative & Western Office
600 N. Olive Street
Media, PA 19063
610-566-7540
Fax 610-566-7677

Eastern Office
37 N. Glenwood Avenue
Clifton Heights, PA 19018
610-626-5800
Fax 610-626-3992

Ralph Moses House
2500 W. 10th Street
Chester, PA 19013
610-859-3806
Fax 610-859-3808

www.fcsdc.org

Testimony Prepared by Ruby J. Benson, Director of Housing Services, Family and Community Service of Delaware County for the United State House Committee on Labor, Health and Human Services, and Education, and Related Agencies addressed to the Department of Health and Human Services

April 15, 2015

Family and Community Service of Delaware County (FCSDC) administers the State Food Purchase Program for Delaware County along with The Emergency Food Assistance Program. There are 11 Delaware County Interfaith Food Assistance Network (DIFAN) centers and 9 Outreach Food Pantries. FCSDC is a member of the Continuum of Care Homeless Services Coalition (HSC) of Delaware County with 14 other service provider agencies.

1.) Why Food and Nutrition Services (FNS) Matter for PWH

While adequate food and nutrition are basic to maintaining health for all persons, good nutrition is crucial for the management of HIV infection. Proper nutrition is needed to increase absorption of medication, reduce side effects, and maintain healthy body weight. Research has identified the virus as an independent risk factor for cardiovascular, liver and kidney disease, cancer, osteoporosis and stroke. Several HIV medications can cause nausea and vomiting and some can affect lab results that test lipids and kidney and liver function. These compounding health effects, caused by the virus and its medications, reinforce the important role a nutrient-rich diet plays in a patient's overall care plan. In addition, providing food and nutrition services can serve to facilitate access and engagement with medical care, especially among vulnerable populations.

The Food and Nutrition Services category within the Ryan White Program includes medical nutritional therapy (MNT) and food and nutrition services (FNS). MNT covers nutritional diagnostic, therapy, and counseling services focused on prevention, delay or management of diseases and conditions, and involves an in-depth assessment, periodic reassessment and intervention provided by a licensed, Registered Dietitian Nutritionist (RDN) outside of a primary care visit. The range of FNS provided through the Ryan White program complements the needs of PWH at any stage of their illness. For those who are most mobile, there are congregate meals, walk-in food pantries and voucher programs. For those whose disease has progressed, home-delivered meals and home-delivered grocery bags complement their medical treatment.

Since 2006, HRSA has included MNT and FNS, provided under the guidance of RDNs, as a clinically effective **core medical service** in the Ryan White Program. These services play a critical role in ensuring that PWH enter and continue in primary medical care, adhere to their medications, and ultimately achieve viral suppression.

2.) FNS as a Care Completion Service Unique to Ryan White

Social and economic interventions, most often in the form of care completion service like food and nutrition services, are fundamental to making health care work for PWH. Support services for PWH are not covered in any comprehensive way by Medicaid or other public insurance initiatives that have been expanded by the Affordable Care Act. As the HIV epidemic in the United States increasingly impacts low-income individuals, support services help stabilize individuals living with or at risk of HIV. When needs are met, and life's emergencies are held at bay, PWH are poised to remain connected to care and treatment.

3.) Access to FNS and the Triple Aim

Access to appropriate food and nutrition services (FNS) are increasingly recognized as key to accomplishing the triple aim of national healthcare reform for PWH.

Better Health Outcomes

When clients get effective FNS and become food secure, they then keep scheduled primary care visits, score higher on health functioning, are at lower risk for inpatient hospital stays and are more likely to take their medicines[i]. Studies show both the health benefits of access to MNT and/or nutrition counseling for people with HIV infections[ii] and the resulting decreases in their healthcare costs. Compare these outcomes to PWH who are food insecure, who have:

- Lower CD4 counts & lower likelihoods of having undetectable viral loads[iii]
- More ER visits[iv] & increased morbidity and mortality[v]
- More missed primary care appointments & reduced use of antiretroviral therapy[vi].

Lower Healthcare Costs

Millions of dollars in healthcare expenditures are saved through the provision of FNS to PWH. A recent study comparing participants in a medically-tailored FNS program vs. a control group within a local managed care organization found that average monthly healthcare costs for PWH fell 80% in first three months after receiving FNS[vii]. If hospitalized, nourished clients' costs were 30% lower, their hospital length of stay was cut by 37% and they were 20% more likely to be able to be discharged to their homes rather than a more expensive institution[viii]. Furthermore, FNS are a very inexpensive intervention. For each day in a hospital saved, you can feed a person a medically-tailored diet for half a year.

Improved Patient Satisfaction

Studies show nutrition counseling improves quality of life[ix]. Members overwhelmingly report that our services help them live more independently, eat more nutritiously and manage their medical treatment more effectively.

4.) FNS and the National HIV/AIDS Strategy (NHAS)

Access to FNS for PWH is fundamental to fulfilling the goals of the NHAS.

- **NHAS Goal: Reducing new HIV infections:** PWH who are food insecure are less likely to have undetectable viral loads in a statistically significant way. Undetectable viral loads prevent transmission 96% of the time[x], thus, FNS is key to prevention[xi].
- **NHAS Goal: Increasing access to care and improving health outcomes for people living with HIV:** PWH who receive effective FNS are more likely to keep scheduled primary care

- visits, score higher on health functioning, are at lower risk for inpatient hospital stays and are more likely to take their medicines[xii].
- **NHAS Goal: Reducing HIV-related disparities and health inequities:** By providing FNS to PWH who are in need largely because of poverty, we improve health outcomes, thereby reducing health disparities[xiii].
- **NHAS Goal: Achieving a more coordinated national response to the HIV epidemic:** There remains a tremendous variation by state in coverage of food and nutrition services both inside and outside of Ryan White, making support for Ryan White HIV Program all the more needed. Ultimately, if we are going to achieve a more coordinated national response to the HIV epidemic and our quest to reduce healthcare spending nationwide, FNS must be included in all healthcare reform efforts, including Ryan White and the ACA.

Conclusion
We are deeply aware of the difficult decisions that face the members of the Committee in the current fiscal environment. Yet, research shows that investment in FNS, with the great return in prevention and retention in HIV care, are vital to lowering the number of new infections in the domestic HIV epidemic and ultimately reducing healthcare costs and preserving healthcare resources for the future. A client's diet can literally have life and death consequences. When people are severely ill, good nutrition is one of the first things to deteriorate, making recovery and stabilization that much harder, if not impossible. Early and reliable access to medically-appropriate FNS helps PWH live healthy and productive lives, produces better overall health outcomes and reduces health care costs.

Along with our colleagues, we appreciate the opportunity to offer this testimony regarding the FY 2017 Appropriations process. We are also pleased to offer our assistance and expertise, including information from our Research Library.

Thank you.

Ruby J. Benson

Ruby J. Benson
Director of Housing Services
Family and Community Service of Delaware County
600 N. Olive Street
Media, PA 19063
610-859-3806
rbenson@fcsdc.org

---

[i] Aidala A, Yomogida M, Vardy Y & the Food & Nutrition Study Team. Food and Nutrition Services, HIV Medical Care, and Health Outcomes. New York State Department of Health: Resources for Ending the Epidemic, 2014. Available at https://www.health.ny.gov/diseases/aids/ending_the_epidemic/docs/key_resources/housing_and_supportive_services/chain_factsheet3.pdf

[ii] Academy of Nutrition and Dietetics (formerly American Dietetic Association). HIV/AIDS Nutrition Evidence Analysis Project at http://www.adaevidencelibrary.com/conclusion.cfm?conclusion_statement_id=250707 Accessed 29 July 2012.
[iii] Aidala A., Yomogida M., and the HIV Food & Nutrition Study Team (2011);
Singe AW, Weiser SD, McCoy, SI. Does Food Insecurity Undermine Adherence to Antiretroviral Therapy? A Systematic Review. AIDS Behav (2015) 19:1510–1526.

[iv] Ibid.
[v] Anema A, Chan K, Yip B, Weiser S, Montaner JSG, Hogg RS. Impact of food insecurity on survival among HIV-positive injection drug users receiving antiretroviral therapy in a Canadian cohort. 141st APHA Annual Meeting, Nov. 2-6, 2013. Boston, MA. Abstract #: 290277

[vi] Aidala A., Yomogida M., and the HIV Food & Nutrition Study Team (2011).
[vii] Gurvey J, Rand K, Daugherty S, Dinger C, Schmeling J, Laverty N. Examining Health Care Costs Among MANNA Clients and a Comparison Group. J Prim Care Community Health. (2013) 4:311-317

[viii]Ibid.

[ix] Rabeneck L, Palmer A, Knowles JB, Seidehamel RJ, Harris CL, Merkel KL, Risser JMH, Akrabawi SS. A randomized controlled trial evaluating nutrition counseling with or without oral supplementation in malnourished HIV-infected patients. J Am Diet Assoc. (1998) 98: 434-438;Schwenk A, Steuck H, Kremer G. Oral supplements as adjunctive treatment to nutritional counseling in malnourished HIV-infected patients: randomized controlled trial. Clinical Nutrition (1999) 18(6): 371-374.
[x] M. S. Cohen *et al.*, Prevention of HIV-1 Infection with Early Antiretroviral Therapy. N. Engl. J. Med.(2011) 365, 493-505 . HPTN 052
[xi] Palar K, Laraia B, Tsai A, Weiser SD Food insecurity is associated with sexually transmitted infections and HIV serostatus among low income adults in the National Health and Nutrition Examination Survey (NHANES) (1999-2010). Presented at the American Public Health Association 141st Annual Meeting, Boston, MA, November 5, 2013.
[xii] Aidala A, Yomogida M, Vardy Y & the Food & Nutrition Study Team. Food and Nutrition Services, HIV Medical Care, and Health Outcomes. New York State Department of Health: Resources for Ending the Epidemic, 2014. Available at
xiii Weiser SD, Frongillo EA, Ragland K, Hogg RS, Riley ED, Bangsberg DR. Food insecurity is associated with incomplete HIV RNA suppression among homeless and marginally housed HIV-infected individuals in San Francisco. J Gen Intern Med. (2009) 24(1):14-20.

Outside Witness Testimony

Andrew Reamer, Research Professor, George Washington Institute of Public Policy, George Washington University, Washington, DC

Prepared for the Subcommittee on Labor, Health and Human Services, and Education, and Related Agencies, Committee on Appropriations, U.S. House of Representatives

Regarding the Bureau of Labor Statistics, U.S. Department of Labor

April 15, 2016

Chairman Cole, Ranking Member DeLauro, and members of the Subcommittee, I am writing in support of the President's budget request for $641 million for the Bureau of Labor Statistics (BLS) in Fiscal Year 2017.

As a research professor at the George Washington Institute of Public Policy, I focus on policies that promote U.S. economic competitiveness. From this perspective, I believe that a fully-funded BLS is essential to the health of the nation's economy. I offer three reasons:

- Congress has given the BLS a number of specific mandates that require adequate resources to fulfill. I summarize these mandates in an appendix to this testimony.
- BLS data—particularly data on employment, unemployment, prices, and productivity—are essential for sound federal macroeconomic policies.
- BLS data enable efficient U.S. labor markets by enabling participants—workers, students, educators, and employers—to make more informed decisions. Better decisions in labor markets will result in employers finding workers with desired skills, workers with high value credentials, and reduced federal expenditures for education and workforce development grants.

Since 2010, however, real appropriations for the BLS have fallen by nine percent and staff capacity by eight percent. As a result, the agency has not been able to fully carry out its mandated responsibilities, to the detriment of the U.S. economy. I encourage the Subcommittee to understand that a relatively small amount of taxpayer funds invested in current, reliable statistics will lead to substantial increases in economic activity as measure by jobs and income.

The value of cutting-edge BLS efforts can be seen in its release today of a new data series on the attainment of industry-recognized certifications and occupational licenses among adults. Subcommittee members may see these data at http://www.bls.gov/cps/certifications-and-licenses.htm.

I encourage the Subcommittee to approve the two BLS budget initiatives to greatly enlarge our understanding of two important dimensions of economic activity—contingent work and

employer-provided training. To the extent that workers receive training through employers, federal expenditures for workforce development can decline.

I very much appreciate the opportunity to provide this testimony, hope the Subcommittee finds it of value, and look forward to the Subcommittee's decision with regard to the BLS.

BLS Mandates from Congress

1) **Nationwide Workforce and Labor Market Information System** – The Secretary of Labor is directed to develop, maintain, and continuously improve, in cooperation with the states, a nationwide workforce and labor market information system that facilitates federal, state, and local policy and program design, implementation, and evaluation; labor market research; and informed decision-making by employers, workers, students, educational agencies, and workforce investment boards.[1] The U.S. Code gives BLS five more focused mandates that fit inside this broader one:
   a) Collect, collate and report at least once each year full and complete statistics on the conditions of labor;[2]
   b) Collect, collate, report, and publish monthly and annual employment and wage statistics by detailed industry and geography;[3]
   c) Operate statistical programs essential for development of . . . national statistical series, including those related to employment and unemployment;[4]
   d) Develop methods for estimating Hispanic unemployment;[5] and
   e) Conduct an annual study of veterans' unemployment.[6]

2) **Determination of Federal Pay by Locality** – Congress declares a policy that: federal pay for employees under the General Schedule be based on equal pay for equal work; federal pay distinctions be maintained in line with work and performance distinctions; within any local pay area, federal pay rates be compatible with non-federal pay rates for the same levels of work; and pay disparities between federal and non-federal employees should be eliminated.[7] In line with these principles, federal pay rates are to be determined on the basis of a number of specified data sources, including these BLS products:
   a) Employment Compensation Index (national)
   b) National Compensation Survey (pay to non-federal workers by occupation and work level, by pay locality)
   c) Unemployment rate (national)
   d) Consumer Price Index (national)
   e) Producer Price Index (national)

3) **Reports on Industrial Production and Productivity** – BLS is directed to:
   a) Collect, collate and report at least once each year full and complete statistics on the products of the nation's labor force and the distribution of these products;[8]

---

[1] 29 USC 49l-2 and 29 USC 2864(d)(2)(E))
[2] 29 USC 2
[3] 29 USC 2
[4] 29 USC 49l-1
[5] 29 USC 8
[6] 38 USC 4110A
[7] 5 USC 5301
[8] 29 USC 2

b) At intervals of not less than two years, . . . report the general conditions of production of the nation's leading industries;[9] and
c) Make continuing studies of productivity and labor costs in the manufacturing, mining, transportation, distribution, and other industries.[10]

4) **Imports Monitoring** – The Secretary of Labor and the Secretary of Commerce are directed to monitor imports of goods and services to identify changes in volume of imports and the impacts on production and employment, by geography.[11]

5) **Occupational Health and Safety Statistics** – The Secretary of Labor is directed to develop and maintain an effective program of collection, compilation, and analysis of occupational safety and health statistics. The program should provide accurate statistics on work injuries and illnesses that include all disabling, serious, or significant injuries and illnesses, whether or not involving loss of time from work, and which involve medical treatment, loss of consciousness, restriction of work or motion, or transfer to another job.[12]

6) **Price Statistics** – While the U.S. Code does not require BLS to produce the Consumer Price Index (CPI), it mandates the use of the CPI over 200 times.

In addition to its congressional mandates, the BLS is charged by the Office of Management and Budget with calculating and publishing seven **Principal Federal Economic Indicators** (PFEIs):[13]

1. Employment Situation (unemployment rate and nonfarm payroll employment)
2. Producer Price Indexes (PPI)
3. Consumer Price Index (CPI)
4. Real Earnings
5. Labor Productivity and Costs
6. Employment Cost Index
7. Import and Export Price Indexes[14]

[9] 29 USC 4
[10] 29 USC 2b
[11] 19 USC 2393(a)
[12] 29 USC 673(a)
[13] OMB, Statistical Policy Directive No. 3: Compilation, Release, and Evaluation of Principal Federal Economic Indicators, September 25, 1985.
[14] OMB, "Schedule of Release Dates for Principal Federal Economic Indicators for 2016," September 2015, p. 3.

Prepared for the House Committee on Appropriations
Subcommittee on Labor, Health and Human Services, Education and Related Agencies
Centers for Disease Control and Prevention, Division of Viral Hepatitis

Testimony for Submission
Mariah Johnson
Coordinator
Hepatitis Appropriations Partnership
mjohnson@NASTAD.org

The Hepatitis Appropriations Partnership (HAP) is a national coalition based in Washington, DC, coordinated by Mariah Johnson at NASTAD (National Alliance of State & Territorial AIDS Directors). The coalition includes community-based organizations, public health and provider associations, national hepatitis and HIV organizations, and diagnostic, pharmaceutical and biotechnology companies. HAP works with policy makers and public health officials to increase federal support for hepatitis prevention, testing, education, research and treatment. On behalf of HAP, we urge your support for increased funding for federal hepatitis programs in the FY2017 Labor-Health-Education Appropriations bill, and thank you for your consideration of the following critical funding needs for hepatitis programs in FY2017:

Agency	**Program**	**HAP Funding Request**
Centers for Disease Control and Prevention	Division of Viral Hepatitis	$62.8 million

According to the Centers for Disease Control and Prevention (CDC), hepatitis mortality rates have increased substantially in the United States over the past decade. In fact, for nearly ten years, deaths from HCV have surpassed deaths from HIV and the CDC now reports that deaths associated with HCV now surpass deaths associated with all 59 other notifiable infectious diseases combined. Addressing HIV co-infection rates, as high as 25 percent for HCV and 10 percent for HBV, remains a significant challenge. Until more is done to address hepatitis it will remain the leading non-AIDS cause of death in people living with HIV. Further, HBV and HCV are the leading causes of liver cancer – one of the most lethal, expensive, and fastest growing cancers in America. As CDC's 2016 *Annual Report to the Nation on the Status of Cancer* show, while overall incidences of, and deaths from, cancer have declined, liver cancer is an exception. Both cases of and deaths from liver cancer are on the rise. While HBV and HCV are completely preventable and treatable, as many as 5.3 million people in the U.S. live with HBV and/or HCV and 50-65 percent of them remain undiagnosed, leaving them vulnerable for progression to liver disease, cancer, and ultimately death. However, as indicated in the April 2016 report from the

National Academies of the Sciences, *Eliminating the Public Health Problem of Hepatitis B and C in the United States*, elimination of hepatitis in the United States is feasible, but only if we dedicate the necessary resources and address the underlying barriers.

Although most people living with HCV, who also have the greatest risk for HCV-related morbidity and mortality, are baby boomers - those born between 1945 through 1965 – hepatitis transmission among young people has skyrocketed in recent years. Just last year, in Scott County, Indiana, an outbreak of nearly 185 cases of HIV, of which more than 90% were already infected with HCV, demonstrated the danger of a public health infrastructure lacking in the basic resources necessary to stop the spread of completely preventable infections. Between 2010 and 2013 there was a significant increase in new HBV and HCV infections, with HCV rising by 150%. States like Indiana, Kentucky, West Virginia, Washington and 25 others have reported increases in HCV, while at least Kentucky, Tennessee and West Virginia have seen increases in HBV. Increases in both HBV and HCV in those areas are tied to increases in injection drug use.

In addition to the above concerns, mother-to-child transmission of hepatitis remains a challenge, again despite the availability of prevention tools. Although hepatitis B vaccination coverage among newborns has increased, it remains below the Healthy People 2020 goals. Approximately 24,000 infants are born to mothers living with HBV, resulting in as many as 1000 perinatal transmissions per year. Additionally, the ongoing HCV epidemic among young people who inject drugs has led to increases, in some areas, of mother-to-child transmission of HCV. Elimination of mother-to-child transmission is possible, with increased vaccination for HBV and early detection and treatment of new hepatitis infections.

Even with these challenges, the availability of effective new curative treatments for HCV, and an effective vaccine and good treatments to control HBV, brings the elimination of HCV and HBV in the United States within our reach, setting the stage for an enormous new public health victory. But not without increased investments in comprehensive, national hepatitis prevention, screening, linkage to care, education and surveillance programs. The CDC's 2010 professional judgment (PJ) budget provided the need estimate of $170.3 million annually from FY2014-FY2017 to comprehensively address HBV and HCV. HAP's request of $62.8 million recognizes the current budgetary limitations while also balancing the very urgent need to accomplish the goals of the *Action Plan for the Prevention, Care, & Treatment of Viral Hepatitis (Viral*

Hepatitis Action Plan), to implement the United States Preventive Services Task Force (USPSTF) HBV and HCV screening recommendations, and to ultimately end the epidemics. HAP recommends that these funds be used on the following priority areas, allocated in proportion to HBV and HCV burden, using available epidemiological data.

Screening and Linkage to Care

The *Viral Hepatitis Action Plan* established a goal of increasing the proportion of persons who are aware of their hepatitis infection to 66 percent for both HBV and HCV. Full implementation of the CDC and USPSTF recommendations for HBV and HCV testing and linkage to care by state Medicaid programs, Medicare, and private health systems and providers are necessary to accomplish these goals. As studies have shown, identifying and treating a person living with hepatitis early, before the disease progresses, as opposed to at later stages both averts advanced liver disease and is cost effective: treating a person living with HCV before there is liver scarring gains, or saves, more than $187,000 per person per year. Increased resources would enable DVH to:

- Work to advance testing in private clinical settings, public health settings, and other settings to increase the number of persons diagnosed with HBV and HCV infection and linked to lifesaving care earlier in their infection
- Explore opportunities for utilizing electronic health records to monitor implementation of CDC/USPSTF recommendations

Surveillance

As testing and linkage to care activities increase and improve, strengthening local and state capacity to execute hepatitis monitoring and surveillance activities takes on an even greater importance. The CDC currently funds only 5 state health departments and 2 local health departments to conduct minimal surveillance in their jurisdictions. CDC also provides funds to state and local health departments, the cornerstone implementers of national public health policies, to coordinate prevention and surveillance efforts via the Viral Hepatitis Prevention Coordinator Program (VHPC). The VHPC program is the only national program dedicated to the prevention and control of the hepatitis epidemics. This program provides funding to support a coordinator position in each jurisdiction, though not enough for a full time position, and leaves little to no money for the provision of public health services, such as surveillance, public

education and access to prevention services like testing and hepatitis A and B vaccinations, which must be cobbled together from other sources year-to-year. Hepatitis disproportionately impacts several communities, particularly people who inject drugs (PWID) – as demonstrated by the Indiana outbreak, men who have sex with men, persons living with HIV, African immigrants and African Americans, Asian immigrants and Asian Americans, Pacific Islanders, Latinos, tribal communities, veterans, and residents of rural and remote areas with limited access to medical treatment or culturally and linguistically-appropriate services. Surveillance is needed in order to adequately address the epidemics in these populations. Increasing funding would allow DVH to:

- Establish a regional health training and technical assistance center to support detection and investigations of new HBV and HCV cases, including mother to child HCV transmission; promote implementation of prevention practices among state/local health departments, substance use disorder treatment programs, correctional organizations, and nongovernmental organizations
- Support the development model projects for the elimination of HCV transmission and related mortality throughout an indicated area
- Increase the number of funded sites to increase surveillance in those jurisdictions hardest hit by the hepatitis epidemics.

Addressing the Emerging Hepatitis C Epidemic Among Young Persons at Risk

HCV prevalence among PWIDs is as high as 70%, and between 20-30% of people who inject drugs acquires HCV each year. This trend is largely due to the prescription opiate epidemic and the transition many young people have made from using opiate pills to injecting heroin. This increase, and the ongoing outbreaks in several states, makes the need to enhance and expand these prevention efforts all the more urgent and underscore the need to prioritize immediate support in the field, strengthening health department and community responses that target youth and young adults, specifically persons who injection drugs, persons under 30 years old, and persons living in rural areas. Increased funding would enable DVH to:

- Investigate networks of transmission in order to improve implementation and evaluation of prevention services

- Promote HBV vaccinations, and HBV and HCV screening in settings that reach and provide services for populations at highest risk for transmission
- In addition to HBV and HCV testing, DVH would assure implementation of prevention services to stop HBV and HCV transmission, including counseling, locally supported syringe services programs, treatment for substance use disorders, and linkage to care treatment for people living with HBV and HCV

Elimination of Mother-to-Child Transmission of Hepatitis B

Due in part to the success of the Perinatal Hepatitis B Coordinator program at CDC's National Center for Immunization and Respiratory Diseases (NCIRD), great strides have been made to reduce HBV among newborns and youth. However, between 800 to 1000 perinatal HBV transmissions still occur each year in the U.S. With increased resources, DVH would:

- Monitor and improve implementation of vaccination of all infants within three days of birth through continued collaborations with birthing hospitals
- Continue to work with state epidemiologists to implement revised state and local reporting criteria for pregnant women and their newborns living with HCV
- Consider routine testing HCV testing for women of child bearing age to identify young women living with HCV who would benefit from treatment, and to provide preventive services to their newborns

As the National Academies of the Sciences and the World Health Organization has recognized, prevention and elimination of hepatitis is a feasible goal and should be a public health priority. It is certainly possible in the United States. We have the tools to accomplish this goal and we hope the FY2017 Labor HHS bill will reflect this priority through the allocation of significant resources to rein in the current epidemics and begin to identify those who are already living with HBV and HCV.

As you contemplate the FY2017 Labor, Health and Human Services, Education and Related Agencies appropriations bill, we ask that you consider these critical funding needs. We thank the Chairman, Ranking Member and members of the Subcommittee, for their thoughtful consideration of our recommendations. Our response to the viral hepatitis epidemics in the United States defines us as a society, as public health agencies, and as individuals living in this country. There is no time to waste in our nation's fight against these epidemics.

Written Testimony of Felice J. Levine, PhD, Executive Director
American Educational Research Association
Institute of Education Sciences, Department of Education
U.S. House, Committee of Appropriations
Subcommittee on Labor, Health and Human Services, Education, and Related Agencies
Fiscal Year 2017 Appropriations
April 15, 2016

Chairman Cole, Ranking Member DeLauro, and Members of the Subcommittee, thank you for the opportunity to submit written testimony on behalf of the American Educational Research Association. Appreciative of these stringent times, we recommend that the Institute of Education Sciences (IES) receive $728 million in Fiscal Year 2017. This recommendation is consistent with that of the Dear Colleague letter that you received on March 24, signed by 27 Members of Congress as well as with the request from the Friends of IES coalition, in which we are a leading member.

AERA is the major national scientific association of 25,000 faculty, researchers, graduate students, and other distinguished professionals dedicated to advancing knowledge about education, encouraging scholarly inquiry related to education, and promoting the use of research to improve education and serve the public good.

With the passage of the Every Student Succeeds Act (ESSA) as well as the Evidence-Based Policymaking Commission Act, we see a bipartisan commitment to evidence-based decision making. In 2016, the budget for IES was just over 1 percent of the Department of Education budget, underscoring the underinvestment in research on education as compared with comparable research and development investments in other fields. As we look ahead to 2017, we anticipate that the ESSA requirements that states, districts, and schools assess the evidence when selecting interventions should if anything amplify the demand for the very work of IES.

Since IES was created in 2002, it has made dramatic contributions to the progress of education. Yet, we in the U.S. have a far way to go to provide high-quality education to all of our students. In addition to old questions that remain unanswered—such as how to best prepare teachers—we have barely begun to understand the opportunities provided by advances in technology. IES needs increased funding to continue our progress, using rigorous research to inform education policy. IES comprises the four national centers listed below. Each serves a critical role in improving the quality of education in the U.S.

National Center for Education Statistics (NCES)

Established by an Act of Congress in 1867, NCES is one of the 13 principal federal statistical agencies in the United States. It collects, analyzes, and reports on education data and statistics on the condition of education in our country; conducts long-term longitudinal studies and surveys; and supports international assessments in accordance with the highest methodological standards and practices for data confidentiality and data security.

Federal, state, and local policy makers rely on over two dozen NCES-supported survey programs, assessments, and administrative data sets, as do schools, educators, and researchers across the country. NCES's annual report, *The Condition of Education,* provides a comprehensive statistical overview of U.S. early childhood, K–12, and postsecondary education.

NCES also provides technical assistance to public and private education agencies and to states improving their statistical systems. Grants from the Statewide Longitudinal Data Systems (SLDS) program supports states to build quality data systems that span early childhood, K–12, and postsecondary education into the labor force. In recent testimony to the House Education and the Workforce Committee, Robert Swiggum, Deputy Superintendent, Georgia Department of Education spoke of the tremendous value of the federal SLDS grant that enabled Georgia to construct a statewide longitudinal system. In his testimony he said that the teachers access to the data has improved their teaching and has been a major factor in the dramatic increase in the state graduation rate from 59% in 2009 to 78% in 2015.

The President has requested a significant increase for this program from $35 million in FY 2016 to $81 million in FY 2017. This would enable states and districts to build on existing work and make possible a new competition in FY 2017, allowing more States to leverage existing data to examine local education issues and concerns and achieve improvements in educational outcomes as have been achieved in Georgia.

NCES is home to the National Assessment of Educational Progress (NAEP), known as the "Nation's Report Card." NAEP is an important resource for identifying long-term trends in educational proficiency in each state and—through the Trial Urban District Assessment—in the largest school districts in the nation.

Furthermore, NCES manages the U.S. participation in international assessments and surveys, which prominently include the Program for International Student Assessment (PISA), the Trends in International Mathematics and Science Study (TIMSS), and the Progress in International Reading Literacy Study (PIRLS). Continued adequate funding for these international assessments, enable NCES to accurately gauge U.S. performance in reading, math, and science in comparison to other countries. This information is particularly useful in a time of increasing global economic competition.

The proposed budget increase would enable NCES to adequately fund the most timely information on several high-priority education policy issues: early childhood development and education, student loan repayment and default, and the development of P-12 and postsecondary information hubs to make accessible actionable data and research.

National Center for Education Research (NCER)

Over the past decade, NCER-funded research has made significant advances in our understanding on a broad range of questions, from how to increase math achievement in pre-school; improve literacy skills in third grade, and reduce drop-out rates. The investments in the research are leading to measurable improvements in classrooms across the country. The Building Blocks curriculum, born out of IES and NSF funded research, has recently been adopted by

Boston, New York City, and several California districts, and is showing positive effects on young children's mathematics and literacy skills.

National Center for Special Education Research (NCSER)

NCSER supports research that investigates how to improve developmental and education outcomes for infants, toddlers, children, and youth with, or at risk of developing, disabilities. Since its creation in 2004 under the Individuals with Disabilities Education Act, NCSER has made important contributions to research goals such as identifying effective interventions for children and youth with autism and supporting the independence of youth with disabilities post high school. Another example of an IES-funded work that is leading to tangible improvements for students is the development of the Early Literacy Skills Builder program, currently being used in nearly 1,300 school districts, has been demonstrating improvements in reading outcomes for students with significant intellectual disabilities.

National Center for Education Evaluation and Regional Assistance (NCEE)

NCEE conducts evaluations of large-scale educational projects and federal education programs and advances the use of IES knowledge by informing the public and reaching out to practitioners with a variety of dissemination strategies and technical assistance programs. The Education Resources Information Center (ERIC) is a well-used resource throughout the Department of Education. In the past year, there were more than 18 million individual sessions—more than 49,500 per day. In addition, the What Works Clearinghouse (WWC) provides valuable information on the findings and methodologies of evaluations of various education practiees and policies. The most viewed practice guides include Assisting Students Struggling with Mathematics: Response to Intervention (RtI) for Elementary and Middle Schools; Reducing Behavior Problems in the Elementary School Classroom; and Improving Reading Comprehension in Kindergarten Through 3rd Grade – being viewed between 30,000 to 50,000 times each.

The investment in resources for IES is small in comparison to the challenging issues that our country faces with respect to quality education and learning. Only the most competitive research, capacity building programs, and data assets are supported by IES, and the yield from IES projects has been high for well more than a decade. Further, IES funding and emphases are a resource for the very concerns that drive this committee and its work. Improving the educational outcomes of our citizens would not only help to solve or prevent future labor and workforce problems but also improve the health and wellbeing of our citizens.

Thank you for the opportunity to submit written testimony in support of $728 million for the Institute of Education Sciences in Fiscal Year 2017. AERA welcomes working with you and your subcommittee on strengthening investments in essential research, data, and statistics related to education and learning.

Granite State Independent Living
gsil
Tools for Living
Life on Your Terms

Concord Main Office
21 Chenell Drive
Concord, NH 03301
603.228.9680
800.826.3700
888.396.3459 (tty)
603.225.3304 (fax)
www.gsil.org

Dover
800.826.3700

Keene
603.355.1208
877.680.4826

Littleton
603.444.0904
800.588.5772

Manchester
603.518.4600
800.773.4033

Nashua
603.881.7144

April 15, 2016

Dear House Committee on Appropriations Subcommittee on Labor, Health and Human Services, Education, and Related Agencies:

My name is Jeff Dickinson, Advocacy Director of Granite State Independent Living (GSIL). GSIL is New Hampshire's Center for Independent Living, a non-profit organization whose mission is to give seniors and people with disabilities the tools they need to remain independent in their homes and communities.

I am writing to support the National Council on Independent Living's request for Congress to reaffirm your commitment to the more than 57 million Americans disabilities by increasing funding in the HHS appropriations for Centers for Independent Living (CILs). I am asking that you increase funding by $200 million, for a total of $301 million for the Independent Living line item in FY 2017.

CILs are cross-disability, non-residential, community-based, nonprofit organizations that are designed and operated by individuals with disabilities. CILs are unique in that they are directly governed and staffed by people with all types of disabilities, including people with mental, physical, sensory, eognitive, and developmental disabilities. Each of the 365 federally funded centers provides five core services: information and referral, individual and systems advocacy, peer support, independent living skills training, and transition services, which were added with the passage of the Workforce Innovation and Opportunity Act (WIOA). From 2012-2014, CILs provided the core services to nearly 5 million people with disabilities, and provided additional services such as housing assistance, transportation, personal care attendants, and employment services to hundreds of thousands of individuals. During this same period, prior to transition being added as a core service, CILs transitioned 13,030 people with disabilities from nursing homes and other institutions into the community.

Transition services were added as a fifth core service with the 2014 reauthorization of the Rehabilitation Act within the Workforce Innovation and Opportunity Act. Transition services include the transition of individuals with significant disabilities from nursing homes and other institutions to home and community-based residences with appropriate supports and services, assistance to individuals with significant disabilities at risk of entering institutions to remain in the community, and the transition of youth with significant disabilities to postsecondary life. This core service is vital to achieving full participation for people with disabilities.

Every day, CILs such as ours are fighting to ensure that people with disabilities gain and maintain control over our own lives. We know that this cannot occur when people reside in institutional settings. Opponents of deinstitutionalization say that allowing people with disabilities to live in the community will result in harm. We know that the 13,030 people with disabilities who CILs successfully transitioned out of nursing homes and institutions from 2012-2014 prove otherwise. Additionally, when services are delivered in an individual's home, the result is a tremendous cost savings to Medicaid, Medicare, and states. Community-based services enable people with disabilities to become less reliant on long-term government supports, and they are significantly less expensive than nursing home placements. We are grateful that Congress demonstrated their understanding and support for community-based services when WIOA was passed and transition was added as a fifth core service.

Since transition services were added as a core service, the need for funding is critical. Moreover, CILs need additional funding to restore the devastating cuts to the Independent Living program, make up for inflation costs, and address the increased demand for independent living services. In 2016, the Independent Living Program is receiving $2.5 million less in funding than it was in 2010. It is simply not possible to meet the increasing demand for services and effectively provide transition services without additional funding. Increased funding should be reinvested from the billions currently spent to keep people with disabilities in costly Medicaid nursing homes and institutions and out of mainstream society.

Centers for Independent Living, including GSIL, play a crucial role in the lives of people with disabilities, and work tirelessly to ensure that people with disabilities have a real choice in where and how they live, work, and participate in the community. Additionally, CILs are an excellent service and a bargain for America, keeping people engaged with their communities and saving taxpayer money. NCIL is dedicated to increasing the availability of the invaluable and extremely cost-effective services CILs provide, and they have submitted written testimony with a similar request. We here at Granite State Independent Living strongly support NCIL's testimony. Thank you for the opportunity to write to you today, and thank you for all of the hard work this committee does on behalf of the nation.

Sincerely,

Jeff Dickinson
Advocacy Director

Name: Pamela Momon

Title: Youth Transition/ Housing Information Specialist

REACH

I am writing to support the National Council on Independent Living's request for Congress to reaffirm your commitment to the more than 57 million Americans disabilities by increasing funding in the HHS appropriations for Centers for Independent Living (CILs). I am asking that you increase funding by $200 million, for a total of $301 million for the Independent Living line item in FY 2017.

CILs are cross-disability, non-residential, community-based, nonprofit organizations that are designed and operated by individuals with disabilities. CILs are unique in that they are directly governed and staffed by people with all types of disabilities, including people with mental, physical, sensory, cognitive, and developmental disabilities. Each of the 365 federally funded centers provides five core services: information and referral, individual and systems advocacy, peer support, independent living skills training, and transition services, which were added with the passage of the Workforce Innovation and Opportunity Act (WIOA). From 2012-2014, CILs provided the core services to nearly 5 million people with disabilities, and provided additional services such as housing assistance, transportation, personal care attendants, and employment services to hundreds of thousands of individuals. During this same period, prior to transition being added as a core service, CILs transitioned 13,030 people with disabilities from nursing homes and other institutions into the community.

Transition services were added as a fifth core service with the 2014 reauthorization of the Rehabilitation Act within the Workforce Innovation and Opportunity Act. Transition services include the transition of individuals with significant disabilities from nursing homes and other institutions to home and community-based residences with appropriate supports and services, assistance to individuals with significant disabilities at risk of entering institutions to remain in the community, and the transition of youth with significant disabilities to postsecondary life. This core service is vital to achieving full participation for people with disabilities.

Every day, CILs are fighting to ensure that people with disabilities gain and maintain control over our own lives. We know that this cannot occur when people reside in institutional settings. Opponents of deinstitutionalization say that allowing people with disabilities to live in the community will result in harm. We know that the 13,030 people with disabilities who CILs successfully transitioned out of nursing homes and institutions from 2012-2014 prove otherwise. Additionally, when services are delivered in an individual's home, the result is a tremendous cost savings to Medicaid, Medicare, and states. Community-based services enable people with disabilities to become less reliant on long-term government supports, and they are significantly less expensive than nursing home placements. We are grateful that Congress demonstrated their understanding and support for community-based services when WIOA was passed and transition was added as a fifth core service.

Since transition services were added as a core service, the need for funding is critical. Moreover, CILs need additional funding to restore the devastating cuts to the Independent Living program, make up for inflation costs, and address the increased demand for independent living services. In

From: REACH of Dallas 214 630 6390 04/14/2016 08:29 #344 P.002/004

2016, the Independent Living Program is receiving $2.5 million less in funding than it was in 2010. It is simply not possible to meet the increasing demand for services and effectively provide transition services without additional funding. Increased funding should be reinvested from the billions currently spent to keep people with disabilities in costly Medicaid nursing homes and institutions and out of mainstream society.

Centers for Independent Living play a crucial role in the lives of people with disabilities, and work tirelessly to ensure that people with disabilities have a real choice in where and how they live, work, and participate in the community. Additionally, CILs are an excellent service and a bargain for America, keeping people engaged with their communities and saving taxpayer money. NCIL is dedicated to increasing the availability of the invaluable and extremely cost-effective services CILs provide, and they have submitted written testimony with a similar request. I strongly support NCIL's testimony.

Sincerely,

Pamela Momon

Chrissy Elzy

Program Director

Southeastern IN Independent Living Center

I am writing to support the National Council on Independent Living's request for Congress to reaffirm your commitment to the more than 57 million Americans disabilities by increasing funding in the HHS appropriations for Centers for Independent Living (CILs). I am asking that you increase funding by $200 million, for a total of $301 million for the Independent Living line item in FY 2017.

CILs are cross-disability, non-residential, community-based, nonprofit organizations that are designed and operated by individuals with disabilities. CILs are unique in that they are directly governed and staffed by people with all types of disabilities, including people with mental, physical, sensory, cognitive, and developmental disabilities. Each of the 365 federally funded centers provides five core services: information and referral, individual and systems advocacy, peer support, independent living skills training, and transition services, which were added with the passage of the Workforce Innovation and Opportunity Act (WIOA). From 2012-2014, CILs provided the core services to nearly 5 million people with disabilities, and provided additional services such as housing assistance, transportation, personal care attendants, and employment services to hundreds of thousands of individuals. During this same period, prior to transition being added as a core service, CILs transitioned 13,030 people with disabilities from nursing homes and other institutions into the community.

Transition services were added as a fifth core service with the 2014 reauthorization of the Rehabilitation Act within the Workforce Innovation and Opportunity Act. Transition services include the transition of individuals with significant disabilities from nursing homes and other institutions to home and community-based residences with appropriate supports and services, assistance to individuals with significant disabilities at risk of entering institutions to remain in the community, and the transition of youth with significant disabilities to postsecondary life. This core service is vital to achieving full participation for people with disabilities.

Every day, CILs are fighting to ensure that people with disabilities gain and maintain control over our own lives. We know that this cannot occur when people reside in institutional settings. Opponents of deinstitutionalization say that allowing people with disabilities to live in the community will result in harm. We know that the 13,030 people with disabilities who CILs successfully transitioned out of nursing homes and institutions from 2012-2014 prove otherwise. Additionally, when services are delivered in an individual's home, the result is a tremendous cost savings to Medicaid, Medicare, and states. Community-based services enable people with disabilities to become less reliant on long-term government supports, and they are significantly less expensive than nursing home placements. We are grateful that Congress demonstrated their understanding and support for community-based services when WIOA was passed and transition was added as a fifth core service.

Since transition services were added as a core service, the need for funding is critical. Moreover, CILs need additional funding to restore the devastating cuts to the Independent Living program, make up for inflation costs, and address the increased demand for independent living services. In

2016, the Independent Living Program is receiving $2.5 million less in funding than it was in 2010. It is simply not possible to meet the increasing demand for services and effectively provide transition services without additional funding. Increased funding should be reinvested from the billions currently spent to keep people with disabilities in costly Medicaid nursing homes and institutions and out of mainstream society.

Centers for Independent Living play a crucial role in the lives of people with disabilities, and work tirelessly to ensure that people with disabilities have a real choice in where and how they live, work, and participate in the community. Additionally, CILs are an excellent service and a bargain for America, keeping people engaged with their communities and saving taxpayer money. NCIL is dedicated to increasing the availability of the invaluable and extremely cost-effective services CILs provide, and they have submitted written testimony with a similar request. I strongly support NCIL's testimony.

Prostatitis Foundation -
Promoting Education & Research
1063 30th Street -
Smithshire, IL 61478

Check the internet
and see the
world wide web page:
http://www.prostatitis.org

"FY2017 written Testimony for the record".

From Mike Hennenfent, President of the Prostatitis Foundation, We seek increased funding for prostatitis research. The Mapp Research Network under the auspices of the NIDDK, a branch of the National Institute of Health has been assigned that responsibility. They are making a significant effort and deserve continued support plus additional funds as they see the need...

Prostatitis is a very common disease that because of its nature is seldom discussed. It does not have the open discussion of either prostate cancer or Interstitial Cystitis. Chronic prostatitis patients are very confused about proper treatment, as are their physicians. Most men have no idea what caused their urinary and sexual dysfunction, is it an early sign of prostate cancer, or perhaps some rare pathogen that cannot be detected by usual means? It was less than twenty years ago, Dr. John Krieger, one of the few earlier researchers announced before the urologists gathered in Orlando Florida for the AUA Annual Meeting that, "Prostatitis is now one of the three major prostate diseases recognized by the National Institute of Health."

The third five year plan underway now is called the Multidisciplinary Approach to the Study of Urologic Chronic Pelvic Pain ((MAPP) The idea was to draw some other medical specialties into prostatitis research. It was evident that basic research including different approaches and methods were needed. A disease so evident in early history and so predominant in all populations the world over (estimated at ten percent) has to have more focused efforts. It is

important to remember prostatitis is a disease of younger men who are not inclined to discuss such matters and have suffered in silence these many years.

The unpaid officers and directors of the Prostatitis Foundation determined in their mission statement that we should educate the public about the prevalence of prostatitis and do what we could to encourage and support research to find the cause and a cure for prostatitis. Our newsletters, webpage and forum are all attempts to serve the public to the best of our ability. We do not receive any government funding and rely on support from patients and their families. The officers and directors do not, and never have, received compensation. Our reward will be to see these patients and their families relieved of the pain and stress of Chronic Prostatitis.

My name is Teresa Favuzzi, I am the Executive Director of the California Foundation for Independent Living Centers. We respectfully request that Congress increase funding in the HHS appropriations for Centers for Independent Living (CILs) by $200 million, for a total of $301 million for the Independent Living line item in FY 2017.

This increase in funding would reaffirm the 2014 reauthorization of the Rehabilitation Act within the Workforce Innovation and Opportunity Act, by appropriating funding to achieve the outcomes intended by Transition Services as a mandated 5th core service for CILs.

CILs are cross-disability, non-residential, community-based, nonprofit organizations that are designed and operated by individuals with disabilities. CILs are unique in that they are directly governed and staffed by people with all types of disabilities, including people with mental, physical, sensory, cognitive, and developmental disabilities.

Each of the 365 federally funded centers provides five core services: information and referral, individual and systems advocacy, peer support, independent living skills training, and transition services, which were added with the passage of the Workforce Innovation and Opportunity Act (WIOA).

From 2012-2014, CILs provided the core services to nearly 5 million people with disabilities, and provided additional services such as housing assistance, transportation, personal care attendants, and employment services to hundreds of thousands of individuals. During this same period, prior to transition being added as a core service, CILs transitioned 13,030 people with disabilities from nursing homes and other institutions into the community.

Transition services were added as a fifth core service with the 2014 reauthorization of the Rehabilitation Act within the Workforce Innovation and Opportunity Act. Transition services include the transition of individuals with significant disabilities from nursing homes and other institutions to home and community-based residences with appropriate supports and services, assistance to individuals with significant disabilities at risk of entering institutions to remain in the community, and the transition of youth with significant disabilities to postsecondary life. This core service is vital to achieving full participation for people with disabilities.

Every day, CILs are fighting to ensure that people with disabilities gain and maintain control over our own lives. We know that this cannot occur when people reside in institutional settings. Opponents of deinstitutionalization say that allowing people with disabilities to live in the community will result in harm. We know that the 13,030 people with disabilities who CILs successfully transitioned out of nursing homes and institutions from 2012-2014 prove otherwise. Additionally, when services are delivered in an individual's home, the result is a

tremendous cost savings to Medicaid, Medicare, and states. Community-based services enable people with disabilities to become less reliant on long-term government supports, and they are significantly less expensive than nursing home placements.

Since transition services were added as a core service, the need for funding is critical. Moreover, CILs need additional funding to restore the devastating cuts to the Independent Living program, make up for inflation costs, and address the increased demand for independent living services. In 2016, the Independent Living Program is receiving $2.5 million less in funding than it was in 2010. It is simply not possible to meet the increasing demand for services and effectively provide transition services without additional funding. Increased funding should be reinvested from the billions currently spent to keep people with disabilities in costly Medicaid nursing homes and institutions and out of mainstream society.

Centers for Independent Living play a crucial role in the lives of people with disabilities, and work tirelessly to ensure that people with disabilities have a real choice in where and how they live, work, and participate in the community. Additionally, CILs are an excellent service and a bargain for America, keeping people engaged with their communities and saving taxpayer money.

We join the National Council for Independent Living in urging you to support Centers for Independent Living.

Sincerely,

Teresa Favuzzi, MSW
Executive Director

Testimony Prepared by Richard Ayoub, Executive Director of Project Angel Food for the United State House Committee on Labor, Health and Human Services, and Education, and Related Agencies addressed to the Department of Health and Human Services

April 15, 2015

Project Angel Food is part of a nationwide coalition, the Food is Medicine Coalition, of over 80 food and nutrition services providers, affiliates and their supporters across the country that provide food and nutrition services to people living with HIV/AIDS (PWH) and other chronic illnesses. In Los Angeles County, we provide over 500,000 medically tailored, home delivered meals annually. Collectively, the Food is Medicine Coalition is committed to increasing awareness of the essential role that food and nutrition services (FNS) play in successfully treating HIV/AIDS and to expanding access to this indispensable intervention for people living with other severe illnesses.

1.) Why Food and Nutrition Services (FNS) Matter for PWH

While adequate food and nutrition are basic to maintaining health for all persons, good nutrition is crucial for the management of HIV infection. Proper nutrition is needed to increase absorption of medication, reduce side effects, and maintain healthy body weight. Research has identified the virus as an independent risk factor for cardiovascular, liver and kidney disease, cancer, osteoporosis and stroke. Several HIV medications can cause nausea and vomiting and some can affect lab results that test lipids and kidney and liver function. These compounding health effects, caused by the virus and its medications, reinforce the important role a nutrient-rich diet plays in a patient's overall care plan. In addition, providing food and nutrition services can serve to facilitate access and engagement with medical care, especially among vulnerable populations.

The Food and Nutrition Services category within the Ryan White Program includes medical nutritional therapy (MNT) and food and nutrition services (FNS). MNT covers nutritional diagnostic, therapy, and counseling services focused on prevention, delay or management of diseases and conditions, and involves an in-depth assessment, periodic reassessment and intervention provided by a licensed, Registered Dietitian Nutritionist (RDN) outside of a primary care visit. The range of FNS provided through the Ryan White program complements the needs of PWH at any stage of their illness. For those who are most mobile, there are congregate meals, walk-in food pantries and voucher programs. For those whose disease has progressed, home-delivered meals and home-delivered grocery bags complement their medical treatment.

Since 2006, HRSA has included MNT and FNS, provided under the guidance of RDNs, as a clinically effective **core medical service** in the Ryan White Program. These services play a critical role in ensuring that PWH enter and continue in primary medical care, adhere to their medications, and ultimately achieve viral suppression.

2.) FNS as a Care Completion Service Unique to Ryan White

Social and economic interventions, most often in the form of care completion service like food and nutrition services, are fundamental to making health care work for PWH. Support services for PWH are not covered in any comprehensive way by Medicaid or other public insurance initiatives that have been expanded by the Affordable Care Act. As the HIV epidemic in the United States increasingly impacts low-income individuals, support services help stabilize individuals living with or at risk of HIV. When needs are met, and life's emergencies are held at bay, PWH are poised to remain connected to care and treatment.

3.) Access to FNS and the Triple Aim

Access to appropriate food and nutrition services (FNS) are increasingly recognized as key to accomplishing the triple aim of national healthcare reform for PWH.

Better Health Outcomes

When clients get effective FNS and become food secure, they then keep scheduled primary care visits, score higher on health functioning, are at lower risk for inpatient hospital stays and are more likely to take their medicines[i]. Studies show both the health benefits of access to MNT and/or nutrition counseling for people with HIV infections[ii] and the resulting decreases in their healthcare costs. Compare these outcomes to PWH who are food insecure, who have:

- Lower CD4 counts & lower likelihoods of having undetectable viral loads[iii]
- More ER visits[iv] & increased morbidity and mortality[v]
- More missed primary care appointments & reduced use of antiretroviral therapy[vi].

Lower Healthcare Costs

Millions of dollars in healthcare expenditures are saved through the provision of FNS to PWH. A recent study comparing participants in a medically-tailored FNS program vs. a control group within a local managed care organization found that average monthly healthcare costs for PWH fell 80% in first three months after receiving FNS[vii]. If hospitalized, nourished clients' costs were 30% lower, their hospital length of stay was cut by 37% and they were 20% more likely to be able to be discharged to their homes rather than a more expensive institution[viii]. Furthermore, FNS are a very inexpensive intervention. For each day in a hospital saved, you can feed a person a medically-tailored diet for half a year.

Improved Patient Satisfaction

Studies show nutrition counseling improves quality of life[ix]. Members overwhelmingly report that our services help them live more independently, eat more nutritiously and manage their medical treatment more effectively.

4.) FNS and the National HIV/AIDS Strategy (NHAS)

Access to FNS for PWH is fundamental to fulfilling the goals of the NHAS.

- **NHAS Goal: Reducing new HIV infections:** PWH who are food insecure are less likely to have undetectable viral loads in a statistically significant way. Undetectable viral loads prevent transmission 96% of the time[x], thus, FNS is key to prevention[xi].
- **NHAS Goal: Increasing access to care and improving health outcomes for people living with HIV:** PWH who receive effective FNS are more likely to keep scheduled primary care

visits, score higher on health functioning, are at lower risk for inpatient hospital stays and are more likely to take their medicines[xii].

- **NHAS Goal: Reducing HIV-related disparities and health inequities:** By providing FNS to PWH who are in need largely because of poverty, we improve health outcomes, thereby reducing health disparities[xiii].
- **NHAS Goal: Achieving a more coordinated national response to the HIV epidemic:** There remains a tremendous variation by state in coverage of food and nutrition services both inside and outside of Ryan White, making support for Ryan White HIV Program all the more needed. Ultimately, if we are going to achieve a more coordinated national response to the HIV epidemic and our quest to reduce healthcare spending nationwide, FNS must be included in all healthcare reform efforts, including Ryan White and the ACA.

Conclusion

We are deeply aware of the difficult decisions that face the members of the Committee in the current fiscal environment. Yet, research shows that investment in FNS, with the great return in prevention and retention in HIV care, are vital to lowering the number of new infections in the domestic HIV epidemic and ultimately reducing healthcare costs and preserving healthcare resources for the future. A client's diet can literally have life and death consequences. When people are severely ill, good nutrition is one of the first things to deteriorate, making recovery and stabilization that much harder, if not impossible. Early and reliable access to medically-appropriate FNS helps PWH live healthy and productive lives, produces better overall health outcomes and reduces health care costs.

Along with our colleagues, we appreciate the opportunity to offer this testimony regarding the FY 2017 Appropriations process. We are also pleased to offer our assistance and expertise, including information from our Research Library.

Thank you.

Richard Ayoub
Executive Director
Project Angel Food
922 Vine Street
Los Angeles, CA 90038
(323) 845-1800
rayoub@angelfood.org

---

[i] Aidala A, Yomogida M, Vardy Y & the Food & Nutrition Study Team. Food and Nutrition Services, HIV Medical Care, and Health Outcomes. New York State Department of Health: Resources for Ending the Epidemic, 2014. Available at https://www.health.ny.gov/diseases/aids/ending_the_epidemic/docs/key_resources/housing_and_supportive_services/chain_factsheet3.pdf

[ii] Academy of Nutrition and Dietetics (formerly American Dietetic Association). HIV/AIDS Nutrition Evidence Analysis Project at http: www.adaevidencelibrary.com conclusion.cfm?conclusion_statement_id=250707 Accessed 29 July 2012.

[iii] Aidala A., Yomogida M., and the HIV Food & Nutrition Study Team (2011):
Singe AW,Weiser SD, McCoy, SI. Does Food Insecurity Undermine Adherence to Antiretroviral Therapy? A Systematic Review. AIDS Behav (2015) 19:I510–1526.

[iv] Ibid.

[v] Anema A, Chan K, Yip B, Weiser S, Montaner JSG, Hogg RS. Impact of food insecurity on survival among HIV-positive injection drug users receiving antiretroviral therapy in a Canadian cohort. 141st APHA Annual Meeting, Nov. 2-6, 2013. Boston, MA. Abstract #: 290277

[vi] Aidala A., Yomogida M., and the HIV Food & Nutrition Study Team (2011).

[vii] Gurvey J, Rand K, Daugherty S, Dinger C, Schmeling J, Laverty N. Examining Health Care Costs Among MANNA Clients and a Comparison Group. J Prim Care Community Health. (2013) 4:311-317

[viii]Ibid.

[ix] Rabeneck L, Palmer A, Knowles JB, Seidehamel RJ, Harris CL, Merkel KL, Risser JMH, Akrabawi SS. A randomized controlled trial evaluating nutrition counseling with or without oral supplementation in malnourished HIV-infected patients. J Am Diet Assoc. (1998) 98: 434-438;Schwenk A, Steuck H, Kremer G. Oral supplements as adjunctive treatment to nutritional counseling in malnourished HIV-infected patients: randomized controlled trial. Clinical Nutrition (1999) 18(6): 371-374.

[x] M. S. Cohen *et al.*, Prevention of HIV-1 Infection with Early Antiretroviral Therapy. N. Engl. J. Med.(2011) 365, 493-505 . HPTN 052

[xi] Palar K, Laraia B, Tsai A, Weiser SD Food insecurity is associated with sexually transmitted infections and HIV serostatus among low income adults in the National Health and Nutrition Examination Survey (NHANES) (1999-2010). Presented at the American Public Health Association 141st Annual Meeting, Boston, MA, November 5, 2013.

[xii] Aidala A, Yomogida M, Vardy Y & the Food & Nutrition Study Team. Food and Nutrition Services, HIV Medical Care, and Health Outcomes. New York State Department of Health: Resources for Ending the Epidemic, 2014. Available at

xiii Weiser SD, Frongillo EA, Ragland K, Hogg RS, Riley ED, Bangsberg DR. Food insecurity is associated with incomplete HIV RNA suppression among homeless and marginally housed HIV-infected individuals in San Francisco. J Gen Intern Med. (2009) 24(1):14-20.

Eldercare Workforce Alliance
Outside Witness Testimony - Fiscal Year 2017 Appropriations
Subcommittee Labor, Health and Human Services, Education and Related Agencies
Committee on Appropriations
United States House of Representatives
April 15, 2016

Written Testimony Regarding Funding Requests for Eldercare Workforce Programs
of the Department of Health and Human Services

Submitted on behalf of the Eldercare Workforce Alliance
Jessica Nagro, Policy & Communications Manager
2519 Connecticut Avenue, NW, Washington, DC 20008
202-505-4817 jnagro@eldercareworkforce.org

By

Nancy Lundebjerg, MPA
Alliance Co-Convener

Michèle Saunders, DMD, MS, MPH
Alliance Co-Convener

Mr. Chairman Cole, Ranking Member DeLauro, and Members of the Subcommittee:

We are writing on behalf of the Eldercare Workforce Alliance (EWA), which is comprised of 31 national organizations united to address the immediate and future workforce crisis in caring for an aging America. As the Subcommittee begins consideration of funding for programs in FY 2017, the Alliance** urges you to provide adequate funding for programs designed to increase the number of health care professionals prepared to care for America's growing senior population and to support family caregivers in the essential role they play in this regard. We hope you will support a total of $45 million for geriatrics programs in Title VII (previously Title VII and VIII[1]) of the Public Health Service Act, $197 million for programs administered by the Administration for Community Living (ACL), $1.7 billion to support the research efforts of the National Institute on Aging (NIA), and $9.7 million for additional workforce programs.

Today's health care workforce is inadequate to meet the special needs of older Americans, many of whom have multiple chronic physical and mental health conditions and cognitive impairments. Without a national commitment to expand training and educational opportunities, the workforce will be even more constrained in its ability to care for the growth in the elderly population as the baby boom generation ages. Reflecting this urgency, HRSA has identified "enhancing geriatric/elder care training and expertise" as one of its top five priorities. Of equal importance is supporting the legions of family caregivers who annually provide billions of hours of uncompensated care that allows older adults to

[1] In December 2014, HRSA combined the existing Title VIII Comprehensive Geriatric Education Program and the Title VII Geriatric Academic Career Award, Geriatric Education Centers, and Geriatric Training for Physicians, Dentists and Behavioral and Mental Health Providers programs into the Geriatrics Workforce Enhancement Program. The FY 2016 Omnibus also consolidated these programs, citing HRSA's combined competition for the program.

**The positions of the Eldercare Workforce Alliance reflect a consensus of 75 percent or more of its members. This testimony reflects the consensus of the Alliance and does not necessarily represent the position of individual Alliance member organizations.*

remain in their homes and communities. The estimated economic value of family caregivers' unpaid care was approximately $470 billion in 2013, an increase from an estimated $450 billion in 2009.

The number of Americans over age 65 is expected to reach 70 million by 2030, representing a 53% increase from today's 46 million older adults. That is why Title VII geriatrics programs, ACL programs that support family caregivers, and the research efforts of National Institute on Aging are so critical to ensuring there are skilled eldercare workers and well-supported family caregivers available to meet the complex and unique needs of older adults. Specifically, we recommend the following levels:

- **$45 million for Title VII Geriatrics Workforce Enhancement Program;**
- **$197 million for Family Caregiver Support Programs;**
- **$1.7 billion for National Institute on Aging; and**
- **$9.7 million for additional workforce programs.**

EWA specifically requests the following levels of funding:

Title VII Geriatrics Workforce Enhancement Program[2]: Request: $45 Million
The Geriatrics Workforce Enhancement Program (GWEP) seeks to improve high quality, inter-professional geriatric education and training to the health professions workforce, including geriatric specialists, as well as increase geriatrics competencies of primary care providers and other health professionals to improve care for this often underserved population. It supports the development of a health care workforce that improves health outcomes for older adults by integrating geriatrics with primary care, maximizing patient and family engagement, and transforming the healthcare system.

GWEP is the only federal program that increases the number of faculty with geriatrics expertise in a variety of disciplines who provide training in clinical geriatrics, including the training of interdisciplinary teams of health professionals.

In FY15, the Title VII geriatrics programs provided continuing education on Alzheimer's disease and related dementias, among other topics, to more than 150,000 providers. Additionally, in academic year 2014-2015 alone, Title VII supported 54 fellows in medicine, geriatrics, dentistry, and psychiatry who cared for older adults. **Overall, in the 2014-2015 academic year, these geriatrics and gerontology programs provided training to more than 200,000 individuals.**

In May 2015, HRSA announced 41 three-year grant funded programs. For FY2017, we request increased funding for this program to close current geographic and demographic gaps in geriatric workforce training.

Administration for Community Living Family Caregiver Support: Appropriations Request: $197 million

[2] In December 2014, HRSA combined the existing Title VIII Comprehensive Geriatric Education Program and the Title VII Geriatric Academic Career Award, Geriatric Education Centers, and Geriatric Training for Physicians, Dentists and Behavioral and Mental Health Providers programs into the Geriatrics Workforce Enhancement Program. The FY 2016 Omnibus also consolidated these programs, citing HRSA's combined competition for the program.

These programs support caregivers, elders, and people with disabilities by providing critical respite care and other support services for family caregivers, training and recruitment of care workers and volunteers, information and outreach, counseling, and other supplemental services.

- Family Caregiver Support Services: **EWA requests $158.5 million.** This program provides a range of support services to approximately 700,000 family and informal caregivers annually in states, including counseling, respite care, training, and assistance with locating services that assist family and informal caregivers in caring for their loved ones.
- Native American Caregiver Support: **EWA requests $8 million.** This program provides a range of services to Native American caregivers, including information and outreach, access assistance, individual counseling, support groups and training, respite care and other supplemental services.
- Alzheimer's Disease Support Services: **EWA requests $10.5 million.** One critical focus of this program is to support the family caregivers who provide countless hours of unpaid care, thereby enabling their family members with dementia to continue living in the community. It funds evidence-based interventions and expands the dementia-capable home and community-based services.
- Lifespan Respite Care: **EWA requests $5 million.** This program funds grants to improve access to respite care for family caregivers of children or adults with special needs.
- Family Support Initiative: **EWA requests $15 million.** The new initiative will encourage use of community assets and opportunities to help families reduce stress, improve emotional well-being, develop support skills and knowledge, and plan for the future. Special attention will be given to efforts that assist families with balancing workforce participation and caregiving responsibilities, and those facing the dual demands of caring for older parents while raising children and/or supporting a family member with disabilities.

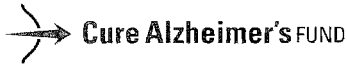
National Institute on Aging: Appropriations Request: $1.7 billion

The National Institute on Aging, one of the 27 Institutes and Centers of the National Institute of Health, leads a broad scientific effort to understand the aging process in order to promote the health and well-being of older adults. Funding will aid in researching training initiatives for the workforce that cares for older adults and research on physician-family communications during end-of-life and critical care.

Additional Workforce Programs: Appropriations Request: $9.7 million

- National Health Care Workforce Commission: **EWA requests $3 million.** The National Health Care Workforce Commission, established by the ACA, plays a central role in formulating a national strategy for bolstering the health care workforce in order to meet the needs of the burgeoning numbers of older Americans. On behalf of the members of the Eldercare Workforce Alliance, thank you for your past support for geriatric workforce programs.
- Geriatric Career Incentive Awards Program: **EWA requests $3.3 million.** Congress authorized this new program through the ACA. Assuming it is extended, these funds foster greater interest among a variety of health professionals in entering the field of geriatrics, long-term care, and chronic care management.
- Training Opportunities for Direct Care Workers: **EWA requests $3.4 million.** In the ACA, Congress approved a program administered by HHS that will offer advanced training opportunities for direct care workers. While this vital training program was left out of President Obama's budget, EWA believes Congress must extend and fund it to create new employment opportunities by offering new skills through training.

On behalf of the members of the Eldercare Workforce Alliance, we commend you on your past support for geriatrics workforce programs and ask that you join us in supporting the eldercare workforce at this critical time – for all older Americans deserve quality care, now and in the future. Thank you for your consideration.



34 Washington Street, Suite 200
Wellesley Hills, MA 02481
ph 781-237-3800
www.curealz.org

Chairman Cole, Ranking Member DeLauro, and members of the House Labor, Health & Human Services, Education, and Related Agencies Appropriations Subcommittee, I am Tim Armour, President and CEO of Cure Alzheimer's Fund. I appreciate the opportunity to thank Congress for the additional funding for Alzheimer's disease research through NIH, and to submit this written testimony to request at least an additional $400 million in Fiscal Year 2017 for Alzheimer's disease research at the National Institutes of Health (NIH).

Cure Alzheimer's Fund is a national nonprofit, based in Massachusetts that funds research throughout the United States and internationally, starting with the genetic aspects of Alzheimer's disease. It is the belief of Cure Alzheimer's Fund that we will not be able to cure the disease if we do not know what causes the disease.

Cure Alzheimer's Fund has a venture philanthropy model which invests in proven talent and empowers them to succeed; invests in ideas early for the biggest possible impact; evaluates potential projects rigorously, but funds them quickly; takes smart risks for the biggest rewards; and has a focused strategy, but is nimble to react to, and take advantage of, new developments. Cure Alzheimer's Fund takes no intellectual property interest in the research it supports.

Since its founding in 2004, Cure Alzheimer's Fund has invested almost $40 million in Alzheimer's research. Often, this investment has been in projects that are considered too risky or early for NIH investment. But because Cure Alzheimer's Fund has provided the vital initial philanthropic investment, researchers are able to prove their concept and compile the necessary data to secure NIH investment.

The $40 million invested by Cure Alzheimer's Fund has led to more than $45 million in NIH grants for a total of more than $85 million invested in Alzheimer's disease research as a result of Cure Alzheimer's Fund's willingness to fund basic research.

The research supported by these investments have led to more than 160 published papers which have been cited more than 10,000 times. This demonstrates the value of "priming the pump" for research and investment in early stage and basic research.

Cure Alzheimer's Fund has assembled a Research Consortium of the leading Alzheimer's researchers. These researchers say that Alzheimer's research is budget, not science, constrained. We are entering a very exciting stage of Alzheimer's disease research with a very real possibility of meeting the National Plan's goal of preventing and effectively treating Alzheimer's disease by 2025.

Recent advancements funded by Cure Alzheimer's Fund include research on the effect of gamma secretase modulators, how beta amyloid is an anti-microbial and part of the body's immune system, moving from gene discovery to therapy development, and the Alzheimer's in a Dish project which will dramatically speed the screening of therapeutic interventions.

These advancements were funded initially by Cure Alzheimer's Fund and then were supported by NIH and others once the proof of concept was established. They are concrete examples of the importance of public-private partnerships and the role each will play in finally curing Alzheimer's disease.

Cure Alzheimer's Fund has worked closely with other advocacy organizations and with Congressional members and staff to showcase the need for additional resources for Alzheimer's disease research. Cure Alzheimer's Fund is very thankful and appreciative of the efforts of this Subcommittee in providing more funding for Alzheimer's disease research at NIH. Cure Alzheimer's Fund realizes how difficult this can be during these times of continuing budget constraints, so it truly appreciates these ongoing efforts by the Subcommittee members and staff, as well as the full Committee members and staff.

For the first time in history, NIH is approaching nearly $1 billion in funding for Alzheimer's disease research funding. This is a more than doubling from where the funding was just a few years ago.

As outstanding as this increase has been, the non-federal members of the Advisory Council established by the National Plan passed by Congress has called for $2 billion a year in Alzheimer's disease research funding being necessary to meet the 2025 goal of the National Plan.

An additional $400 million for Alzheimer's disease research at NIH would be another step in the right direction in meeting the $2 billion investment level called for by the research community. And it would be an important step toward ensuring that promising research funded by organizations like Cure Alzheimer's Fund will have the necessary resources available for it to continue on the discovery continuum without interruption.

Cure Alzheimer's Fund see itself as a partner in this process. It realizes that both government and private organizations have an important role in reaching the day when we can say we have cured Alzheimer's disease. We must all worked together to reach this goal.

Because of this, Cure Alzheimer's Fund fully endorsed the House Report Language last year calling on NIH and private organizations to develop a system to generate investment in meritorious but unfunded grants at NIH. Cure Alzheimer's Fund, along with other organizations, has been working with NIH on this, and the hope is to have a system in place shortly to spur greater research investment.

This system would allow private organizations to identify worthy research proposals that match their own organizational focus and expertise. It would help get early investment into promising research and would generate more understanding of Alzheimer's disease and targets for intervention. It could be a model for public-private partnerships in other diseases.

But for the partnership to work effectively, there needs to be sufficient public investment in Alzheimer's disease research. An at least additional $400 million for Alzheimer's disease research at NIH would support even more new discoveries that can be fully vetted and developed.

As we all know, we are paying for Alzheimer's disease already. Alzheimer's disease is the only Top Ten Mortality condition that has its mortality rates increasing. It is the only condition without a therapeutic intervention. It is the only condition that will bankrupt the Centers for Medicare &Medicaid Services. It has to be stopped.

Cure Alzheimer's Fund knows that as it is asking Congress for additional funding, it must also increase its commitment. In 2015, Cure Alzheimer's Fund more than doubled its yearly commitment to research funding to more than $10 million. The goal for 2016 is to have an additional increase of approximately 25% to $12.5 million.

Cure Alzheimer's Fund sees the advancements being made in Alzheimer's disease research and the opportunities these advancements are creating. As I stated earlier, we are entering a very exciting and productive time for Alzheimer's disease research. Cure Alzheimer's Fund has worked closely with the Subcommittee in the past and looks forward to working with it in the future as we continue toward our shared goal of curing Alzheimer's disease.

The Subcommittee has shown its commitment to this issue, and at times when allocating additional funding has not been easy. But know that this increased funding has produced much progress in combatting Alzheimer's disease. As this progress is being made, I hope that it can continue with increased research funding.

Thank you for the opportunity to submit this written testimony and to respectfully request at least an additional $400 million in Fiscal Year 2017 for Alzheimer's disease research at NIH. Cure Alzheimer's Fund looks forward to working with you as the appropriations process continues and to being a resource to the Subcommittee on Alzheimer's disease research issues.

Respectfully Submitted April 15, 2016 by:

Timothy Armour
President and CEO
Cure Alzheimer's Fund
34 Washington Street, Suite 200
Wellesley, MA 02481

office: 781-237-3801
fax: 781-658-2399
tarmour@curealz.org

Outside Witness Testimony – Fiscal Year 2017 Appropriations

Submitted by:
WestCare Foundation

Prepared for:
The United States House Committee on Appropriations
Subcommittee on Labor, Health and Human Services, and Education, and Related Agencies

Agencies:
Centers for Disease Control, Substance Abuse and Mental Health Services Administration

April 15, 2016

WestCare Foundation respectfully submits this testimony to the U.S. House Appropriations Subcommittee on Labor, Health and Human Services, and Education, and Related Agencies (LHHS) regarding Fiscal Year (FY) 2017 appropriations for the Center for Disease Control (CDC) Prevention for States Program, a funding request of $80 million, and the Substance Abuse and Mental Health Services Administration (SAMHSA), requesting sufficient funding to address the opioid and prescription drug epidemic.

Each day, 46 people in the United States die from overdose of prescription painkillers[1]. According to the CDC, people in rural communities are nearly twice as likely to overdose on prescription pain medications as people in cities[2]. Prescription drug and opioid abuse is a public health crisis of significant proportion, in which underserved, rural areas are hit the hardest. Offering a full continuum of services to individuals with substance use disorders (SUD), including evidence-based prevention, early intervention and treatment efforts, is a necessary and comprehensive approach to combatting prescription drug overdose and sustaining recovery.

WestCare Foundation is a national non-profit organization that provides a wide array of health and human services in both outpatient and residential environments in nearly 20 States and the Pacific and Caribbean Islands. The Foundation provides comprehensive, wrap-around substance abuse and mental health services for children, adolescents, adults, and families, with an emphasis on serving underrepresented populations in rural areas. WestCare programs have shown significant outcomes in treating veteran and criminal justice populations returning to their communities through recovery supports such as housing, education, employment and other transitional services.

As a national substance use disorder provider, WestCare Foundation recognizes the magnitude of the prescription drug and opioid public health crisis our nation faces, and emphasizes the collaborative role of states, local communities, and service providers in preventing prescription

[1] Center for Disease Control (CDC): http://www.cdc.gov/vitalsigns/opioid-prescribing/ (2014)
[2] Center for Disease Control (CDC): http://www.cdc.gov/vitalsigns/painkilleroverdoses/ (2011)

drug overdoses, in addition to the importance of a continuum of care in effectively curbing substance use and mental health disorders through affordable and accessible care.

Center for Disease Control (CDC)

WestCare Foundation supports the Administration's FY 2017 request for $80 million for prescription drug overdose prevention programming at the Centers for Disease Control (CDC), $10 million above FY 2016 enacted levels.

The Center for Disease Control's (CDC) Prescription Drug Overdose Prevention for States Program (Prevention for States) is an initiative implemented in 2015 to provide state health departments with resources and support needed to advance interventions for preventing prescription drug overdoses within four key strategy areas: 1) Enhancing and maximizing state Prescription Drug Monitoring Programs (PDMPs) 2) Implementing community or insurer/health systems interventions 3) Conducting policy evaluations and 4) Developing and implementing rapid response projects. Due to the effectiveness of the program and the rising need, CDC received substantial increases in FY 2015 of $20 million, and in FY 2016, of $50 million dollars, to expand the state prevention activities to a national scale.

To ensure accountability, measurable outcomes and tracked progress, CDC is undergoing an evaluation of the program in order for measures to inform program improvements to achieve the highest public health impact possible as this program continues to grow and expand.

In FY 2017, the President's budget requests $80 million for prescription drug overdose prevention to promote opioid prescribing guideline dissemination and uptake. The Administration's budget proposal includes funding to continue and expand upon state support for Prescription Drug Overdose Prevention Programs in all 50 states and Washington, D.C., and continue to allow rigorous monitoring and evaluation and improvements in data quality.

In Fiscal Year 2017, WestCare Foundation supports the Administration's appropriations request for prescription drug overdose prevention of $80,000,000. This investment will increase accountability for States and allow States to advance and expand interventions for preventing prescription drug overdoses.

Given the prevalence of prescription drug and opioid abuse in rural areas throughout the nation, **WestCare recommends CDC outline a new strategic goal within the Prescription Drug Overdose Prevention for States Program dedicated to rural outreach,** engaging underserved communities through the existing U.S. Department of Agriculture (USDA) Cooperative Extension Service program (Extension Program).

By utilizing existing infrastructure such as Extension Programs, we can build on and connect services already underway such as SAMHSA Block Grants, SAMHSA Drug Free Communities, CDC Prevention for States, and HRSA grantees and streamline federal efforts to increase local and federal collaboration. Lack of local-federal and interagency coordination has impeded efficient, collaborative efforts among local stakeholders.

In February 2016, Secretary Tom Vilsack of USDA announced the "Rural America Opioid Initiative" to address the shortage in substance abuse services in rural areas. This interagency initiative has potential to serve as an effective vehicle in coordinating federal efforts to combat the opioid and heroin public health crisis in rural America. Through interagency coordination between the CDC and USDA, states and local communities can capitalize on existing programs like the USDA Extension Program and the CDC Prevention for States Program. Specifically, WestCare recommends that the CDC Prevention for States Program require grantees to provide Extension Offices with the resources, best practices, and technical expertise necessary to guide and assist local communities and rural SUD treatment providers in expanding treatment capacity and coordinating federal, state, and local opioid initiatives and funding streams at the local level.

WestCare respectfully recommends the following report language be inserted into the Fiscal Year 2017 Labor, Health and Human Services, Education, and Related Agencies Appropriations Bill: "the Committee directs the agency [CDC] to offer a new Prescription Drug Overdose Prevention for States Program competition [in Fiscal Year 2017] that incorporates a strategic goal to implement effective prescription drug overdose prevention in underserved rural areas, provided that up to 2% of funds under the program may be retained for an annual national summit on opioid treatment in rural communities."

Substance Abuse and Mental Health Services Administration (SAMHSA)

In FY 2017, WestCare Foundation supports increased investment to address prescription opioid abuse and heroin use, and is encouraged by the significant attention to substance use disorder treatment expansion, provided that medication-assisted-treatment is coupled with the full continuum of behavioral therapy and recovery support services. As physicians become gate keepers it is also imperative that they are highly qualified in diagnosing behavioral health disorders, treating addiction as a disease, proper pain prescribing, providing person-centered recovery plans, and making appropriate referrals to behavioral health specialists as they would for another health disorder.

WestCare Foundation applauds the Administration's and Congress' attention to the opioid and heroin epidemic, but recommends that any investment in medication-assisted treatment emphasize and provide flexibility for individualized, patient-centered behavioral and recovery support services. Substance addiction is a chronic, relapsing disease with prescribed care regimens that are often comparable to diabetes or heart disease, requiring patient education, treatment, rehabilitation, and consistent management of the disease upon recovery. Treatment modality, length of stay and service provision must be taken into consideration and will vary depending on the duration, dose and type of substance use, as well as the age of first initiation, trauma experienced, and other physical and mental health co-occurring disorders.

As with other chronic conditions treated with medication, medication-assisted treatment may facilitate stabilization and recovery for an opioid disorder. However, similar to a diabetic who receives insulin without changing their behavior and lifestyle through diet and exercise, an individual suffering from opioid addiction who receives medication-assisted treatment without complementary behavioral and recovery support services may not achieve sustained recovery.

Medication-assisted-treatment used in combination with necessary behavioral support services may help substance-addicted individuals to sustain their recovery.

SUDs are present on a wide spectrum of severity, often with co-occurring mental health and primary care health issues. To address the range of issues, WestCare provides differentiated programs across the continuum of care – services to accompany medication-assisted treatment. WestCare's wrap-around services include outpatient and residential treatment programs that include assessment, individual and group counseling, and case management; family and transitional education; vocational education; recreational therapy; health and mental health promotion; permanent and temporary supportive housing; and other community and peer supports.

One of the most pressing barriers to comprehensive services is workforce capacity and access to treatment. People seeking treatment are usually at their lowest point and impressionable. When forced to wait for treatment service, hopelessness can manifest and increase the likelihood for relapse. Unfortunately, the existing community-based system of care for heroin and opioid disorders is restricted by the Institute of Mental Disease (IMD) exclusion at a time when greater capacity is an essential respond to the crisis.

Medication-assisted treatment has been shown to improve patient survival, increase retention in treatment, decrease illicit opiate use and other criminal activity among people with substance use disorders, increase patients' ability to gain and maintain employment, improve birth outcomes among women who have substance use disorders and are pregnant[3].

Despite this evidence-based approach and proven effectiveness, medication-assisted-treatment is greatly underused. According to SAMHSA, the number of heroin admissions with treatment plans that included receiving medication-assisted opioid therapy fell from 35% in 2002 to 28% in 2010[3]. Slow adoption of these treatment options is partly due to misconceptions about substituting one drug for another and lack of training for physicians. Now, medication-assisted treatment is being looked to as a primary and sustainable method to provide comprehensive treatment.

The CDC Guideline for Prescribing Opioids for Chronic Pain released in March of 2016 recommends clinicians "offer or arrange evidence-based treatment (usually medication-assisted treatment with buprenorphine or methadone in combination with behavioral therapies) for patients with an opioid use disorder[4]." As an extension, the CDC points to studies that suggest using behavioral therapies, in combination with treatments like methadone maintenance therapy or buprenorphine, can reduce opioid misuse and increase retention during maintenance therapy and improve compliance after detoxification[5].

As both providers and policy-makers look to medication-assisted treatment models, the importance of behavioral therapy and full recovery support cannot be overstated. Therefore, **WestCare Foundation respectfully requests that any funding appropriated by Congress for medication-assisted treatment include report language explicitly stating "medication-assisted treatment**

---

[3] SAMHSA Treatment Episode Data Set (TEDS) 2002-2010: http://store.samhsa.gov/product/2000-2010-National-Admissions-to-Substance-Abuse-Treatment-Services/SMA12-4701

[4] CDC Guideline for Prescribing Opioids for Chronic Pain — United States, 2016: http://www.cdc.gov/mmwr/volumes/65/rr/rr6501e1.htm

in conjunction with behavioral and recovery support services" as an allowable use of medication-assisted treatment funds. The intention is to provide sufficient flexibility to allow substance use disorder treatment providers to meet local needs of their individual communities and target vulnerable populations such as pregnant women and veterans.

In closing, WestCare Foundation recognizes the fiscal realities of the federal budget but remains encouraged by Congress' strong commitment to addressing our nation's substance abuse public health crisis. We support the highest possible funding for mental health and substance use disorder treatment in FY 2017, and believe that through greater coordination of existing programs we can improve and better document treatment outcomes for people who suffer from addictions and or co-occurring disorders. We strongly encourage the Subcommittee not to overlook the need of coordination, capacity building, and the break-down of federal funding silos at the most local levels, particularly in rural communities. We further urge the Subcommittee not to view medication-assisted treatment as a "silver bullet," quick solution to our nation's opioid public health crisis – medication must be paired with complementary behavioral support services to achieve long-term, sustainable recovery. We look forward to collaborating on the FY 2017 appropriations process as Congress looks to invest and direct resources to this critical, national issue.

- 75% of Republicans and 92% of Democrats;
- 86% of respondents in the West, 84% in the South, 82% in North Central, and 79% in the Northeast; and
- 88% of African Americans, 83% of Whites, and 81% of Hispanics.

Some have proposed "equal" funding for abstinence-only programs and TPPP, but this misses the point that it is the outcomes and not the content that should set the standard. For example, there are several program models on the OAH list of effective programs that teach about both abstinence and contraception and that have been shown through careful evaluation to delay sex among the teens who participate—i.e., abstinence is the result. By focusing on results rather than the decades-old fight over content, TPPP contributes to the universal goal of reducing teen pregnancy.

There are many well-meaning programs—both those that teach only abstinence and those that teach both abstinence and contraception. However, only a small proportion of these programs have actually been proven by rigorous evaluation standards to change behavior, and those are the kinds of high quality programs that TPPP supports.

We recognize that Congress faces tough budget decisions. TPPP, when combined with one other evidence-based federal funding stream for teen pregnancy prevention, still only serves roughly two percent of all teens. Furthermore, TPPP grants are highly competitive and demand far outpaced available funding. More than 400 applications were submitted for the current round of grants, but OAH only had sufficient funding to award 81 grants, or approximately 19% of the applications. To put the $110 million request for TPPP in context, it represents .07% of the FY 2017 LHHS 302(b) allocation adopted by the Senate Appropriations Committee for FY 2017.

Reducing teen pregnancy helps reduce poverty, increase educational achievement and workforce competitiveness, and improve the health and well-being of children and families. TPPP helps achieve this goal by adhering to the highest standards of evidence, focusing on outcomes rather than program content, and ensuring the growth and support of a broad menu of proven program models that communities can choose from. Given the costs and consequences associated with teen pregnancy, providing $110 million for this evidence-based program is a smart investment that will ensure that federal dollars are spent most effectively.

In closing, thank you for considering this testimony submitted in support of restoring full funding to OAH's evidence-based teen pregnancy prevention program. If you have any questions or need additional information, please contact me at 202-478-8529 or rfey@thenc.org.

Sincerely,

Rachel Fey
Director, Public Policy

[1] http://thenationalcampaign.org/resource/fast-facts-teen-pregnancy-united-states

[2] http://thenationalcampaign.org/resource/teen-childbearing-united-states-2014-birth-data
[3] http://thenationalcampaign.org/resource/fast-facts-teen-pregnancy-united-states
[4] http://thenationalcampaign.org/resource/counting-it-how-use-cost-data-your-community
[5] http://thenationalcampaign.org/resource/briefly-unplanned-pregnancy-among-college-students
[6] http://thenationalcampaign.org/resource/survey-says-plus-july-2015
[7] http://thenationalcampaign.org/resource/survey-says-plus-july-2015
[8] http://thenationalcampaign.org/resource/survey-says-july-2015

Submitted by Lisa Van Doren
Vice President & Chief of Staff, Government Affairs
National Council of Farmer Cooperatives

Statement on Behalf of
American Farm Bureau Federation
AmericanHort
Florida Fruit & Vegetable Association
National Council of Agricultural Employers
National Council of Farmer Cooperatives
U.S. Apple Association
United Fresh Produce Association
USA Farmers
Western Growers

Submitted to the
House Appropriations Subcommittee on Labor, Health and Human Services, and Education, and Related Agencies
U.S. House of Representatives

Regarding the

Department of Labor

April 15, 2016

Chairman Cole, Ranking Member DeLauro, and members of the Subcommittee, thank you for your continued leadership and support for U.S. agriculture. The above signed steering committee members of the Agriculture Workforce Coalition appreciate this opportunity to submit our views regarding the FY 2017 Labor, Health and Human Services, and Education, and Related Agencies appropriations bill, and respectfully requests this statement be made part of the official hearing record.

The labor situation in agriculture has been a concern for many years, but is moving towards a breaking point. Today, large segments of American agriculture face a critical lack of workers, a shortage that makes our farms and ranches less competitive with food from abroad and that threatens the abundant, safe and affordable domestic food supply American consumers enjoy today.

Repeated evidence over the past decades has shown that there are some jobs in agriculture that Americans simply do not want to do. Although many of these jobs offer wages competitive with similar, non-agricultural occupations, they are physically demanding, conducted outdoors in all seasons and weather, and are often seasonal or transitory. It is for this reason that farmers have grown to rely on foreign workers to perform this work.

The overarching challenge to workforce stability in agriculture is the widely acknowledged lack of authorized work status by a large number of agricultural workers despite the prevalence of documentation presented by workers to the contrary. The only option for farmers and ranchers to legally find the workers they need is the H-2A temporary work visa program, a program that has not worked for many agricultural employers.

The H-2A program's basic framework is overly restrictive and difficult to maneuver. Furthermore, the H-2A program is only accessible for producers with seasonal needs; excluding the year-round needs of many producers such as dairy, livestock, mushrooms, and other crops. In recent years the program has become even more bureaucratic, burdensome and costly to use. But, each year, more and more farms have to turn to the H-2A program for legal foreign labor to meet their workforce needs.

The demand on the program is increasing as producers have nowhere else to turn; yet the administrative weight of the program cannot keep up. H-2A employment has doubled in the past four years and will double again in the next two years or less. Even at current levels, capacity and infrastructure issues at the Departments of State, Homeland Security and Labor are leading to greater processing delays than ever before. This means bureaucratic red tape and delays in the program result in workers showing up at the farm well after the date they were needed to be there, and millions of dollars in agricultural production is lost in the interim.

To improve the function of the H-2A program, we seek the following as part of the FY2017 Labor, Health and Human Services, and Education, and Related Agencies Appropriations bill:

Farm Labor Survey Wage Categories

Agency: Department of Labor
Program: Farm Labor Survey
Justification: Allows for more detailed data collection and normalizes the data with Occupational Employment Statistics categories used by the Department of Labor.
Language Type: Bill
Proposal: No such sums shall be provided for the determination pursuant to 20 CFR 655.120 unless the Secretary determines the weighted average annual rate for field workers separately from livestock workers and equipment operators and provides a rate for field workers and a separate rate for livestock workers and equipment operators.

Advertising

Agency: DOL Employment and Training Administration
Program: H-2A Program
Justification: The H-2A program's basic framework is overly restrictive and difficult to maneuver. The traditional newspaper advertising requirement is another example of sheer inefficiencies. In this modern day farmers should not be required to place costly job postings in newspapers, but rather use the already existing DOL State Workforce Agency's online tools.
Language Type: Bill

Proposal: No such sums shall be used to implement or enforce 20 CFR 655.121, as long as the employer is using the Department of Labor State Workforce Agency's online system for advertising methods.

Staggered Entry

Agency: Department of Labor – Office of Foreign Labor Certification
Program: H-2A Program
Justification: This modification was recommended by the Government Accounting Office in a September 2012 report, which stated that to reduce the burden on agricultural employers and improve customer service, the Secretary of Labor should permit the use of a single application with staggered dates-of-need for employers who need workers to arrive at different points of a harvest season.
Language Type: Bill
Proposal: No such funds may be used to implement 20 CFR 655 unless provisions are made to allow for staggered entry dates for workers defined in 8 USC 1101(a)(15)(H)(ii)(A). *(NOTE: Staggered entry for seafood was included under H-2B in the FY2016 omnibus: Division H, Title 1, Sec. 111, page 358)*

Limitations on NFJP

Agency: Department of Labor
Program: Migrant and Seasonal Farmworker Programs under Section 167 of the Workforce Innovation and Opportunity Act
Account: 016–0174–0–1–504-0011
POTUS Budget: Page 787
Justification: At a time of increased labor shortages in the agricultural sector, the Federal government should not continue spending money to exacerbate this problem, but should instead be directing these funds in a manner that will enhance skills needed for agricultural work.
Language Type: Bill
Proposal: No such funds may be used for training purposes under Section 167 of the Workforce Innovation and Opportunity Act unless the training is dedicated to skills improvement for workforce development in all aspects of agricultural operations.

Corresponding Employment

Agency: Department of Labor Office of Foreign Labor Certification
Program: H-2A Program
Justification: From 1987 until 2010, DOL interpreted the term corresponding employment to mean that a US worker who performed all the duties in the occupation defined in the job order was in corresponding employment with H-2A workers and had to be provided the same wages and benefits as the H-2A worker. In 2010, DOL changed the wording of the regulation to state that any US worker who performed any activity in the job order was in corresponding employment. The adverse consequence is that an H-2A worker may perform highly skilled work most of the time but occasionally performs very basic unskilled work. If the H-2A worker performs any unskilled work, then the 2010

rule sweeps the entire US workforce incapable of performing the skilled work defined in the job order into corresponding employment, forcing the employer to pay unskilled workers the same as highly skilled workers.
Language Type: Bill
Proposal: No such funds shall be used to implement the definition of corresponding employment (20 CFR 655.103) unless it is implemented consistent with the final 1987 regulation (29 CFR § 501.0, 52 Fed.Reg. page 20524) to read that "the employment of workers who are not H-2A workers by an employer who has an approved H-2A application for Temporary Employment Certification in the occupation described in the job order performed by H-2A workers and for the time period set forth in the approved job order."

Commuter Housing

For operations along the southern border, workers commute daily from their homes in Mexico. Required housing that is provided to these workers goes unused and is therefore an unnecessary cost imposed on employers.

Agency: DHS U.S. Citizenship & Immigration Services and DOL Wage and Hour Division
Program: H-2A Program
Proposal: 8 USC 1188(c)(4) is amended as follows: the housing requirement for H-2A workers is waived when the job site is within 50 miles of the border and the worker's place of residence is within normal commuting distance.

We remain steadfast in our pursuit of broader immigration reform that meets both the short- and long-term workforce requirements of all of agriculture—both those producers with seasonal labor needs, and those with year-round needs. Yet we recognize such reforms may not come to fruition in the near term.

Left with no other alternative, we seek your support for the inclusion of these modest adjustments as you prepare FY2017 appropriations legislation.

Thank you again, and members of the Subcommittee, for the opportunity to share our views.

Testimony of Jean Desravines, CEO, New Leaders

Prepared for the House Appropriations Subcommittee on Labor, Health and Human Services, Education, and Related Agencies

Re: U.S. Department of Education

- **School Leader Recruitment and Support Program - $30 million**
- ***Updated* Teacher Quality Partnerships Program - $125 million**

Thank you for the opportunity to provide testimony regarding the FY2017 Labor, Health and Human Services, Education, and Related Agencies Appropriations bill. New Leaders is a national nonprofit organization dedicated to providing all children with a high-quality education that prepares and inspires them be successful in college, career, and citizenship. To achieve this critical goal, we develop transformational school leaders to serve the nation's highest-need communities and we advance the policies and practices that allow great leaders across the country to be successful. Since 2001, we have developed 2,500 leaders who are currently supporting 450,000 students, most of whom are students of color and come from low-income backgrounds.

New Leaders is committed to making every school a place where great teachers love to teach and all students love to learn. 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. We were pleased that the *Every Student Succeeds Act* (ESSA), passed by Congress in December 2015 to reauthorize the *Elementary and Secondary Education Act* (ESEA), maintains and strengthens several programs that provide critical support for school leadership. In addition, the authorizing language repeatedly emphasizes the important role of principals and school leaders, clearly demonstrating that Congress understands the relationship between strong school leadership and student success.

The current appropriations process is an opportunity for Congress to solidify its support for school leaders and show its commitment to improving student outcomes by making meaningful investments in the programs that will enable and empower great principals to create schools where teachers can thrive and students can excel.

As you consider FY2017 appropriations legislation, we urge you to provide robust funding for two programs specifically dedicated to fostering highly-effective school leaders: the School Leadership Retention and Support Program (SLRSP) and an updated Teacher Quality Partnerships (TQP) program.

1 | © 2016 New Leaders, Inc. All Rights Reserved.

- **The School Leadership Recruitment and Support Program** (SLRSP) was authorized under ESSA with bipartisan support. SLRSP updates the School Leadership program (SLP, the program included in the previous version of ESEA) and will give high-poverty districts 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, including 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 (IHEs). 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. For example, Oakland Unified School District started partnering with New Leaders shortly after the passage of No Child Left Behind to strengthen leadership in its lowest-performing schools. New Leaders' growth in the district was made possible by an SLP grant. With leadership as a key district initiative, Oakland achieved the status of most-improved urban district for eight years in a row, outpacing the state's Academic Performance Index (API) growth by as much as 25 percent annually. While there's more work to be done, today Oakland schools are vastly different from what they were before the district decided to prioritize school leadership and rethink its approach to principal preparation and support—a reality truly made possible by strategic, timely federal SLP support. **We strongly recommend that Congress allocate at least $30 million for SLRSP in FY2017, in line with the Administration's budget request and sufficient to carry out a new school leadership competition during the critical planning year before full ESSA implementation takes place in SY2017-18.**

- **The Teacher Quality Partnerships Grant Program** (TQP) funds partnerships among IHEs and high-need LEAs to create model teacher and principal preparation programs. We support the goals of the TQP program—increasing student achievement by improving the quality of new prospective teachers—and encourage continued funding for this program at $125 million. However, we also believe federal lawmakers should take steps to strengthen the program and, in particular, ensure that it reflects the importance of school leaders. First, TQP should fund partnerships among high-performing educator preparation programs (including those run by both IHEs and nonprofit organizations) and

---

high-need LEAs. Current law needlessly restricts eligibility and prevents proven, non-university-based programs from applying—doing a significant disservice to high-need LEAs that wish to partner with an alternative program that best meets its talent needs. In addition, TQP should allow grantees to use funds to support programs that prepare teacher leaders and principals, regardless of whether the partnership also intends to prepare teachers. Finally, to strengthen our collective understanding of the types of programs that prepare highly effective educators, TQP should require grantees to report on key outcomes measures, including those related to graduates' placement and retention in relevant positions and their influence on student achievement, among other potential measures. Ideally, the recommendations listed above would be incorporated into the reauthorization of the Higher Education Act. Given the limited time left to legislate this year, we believe that the President's proposed Teacher and Principals Pathway program could serve as an opportunity to update and replace TQP. **We support $125 million in funding for the Teacher and Principal Pathways program proposed in the Administration's FY2017 budget request, including $35 million dedicated specifically to principals.**

In addition to SLRSP and TQP, there are a number of other programs that have the potential to positively impact school leadership.

The Education Innovation and Research (EIR) program provides support and creates a framework for developing, validating, and scaling up effective, innovative interventions for addressing persistent education challenges. Therefore, EIR can play a key role in identifying and expanding school leadership development programs that truly have a positive effect on student achievement and school performance, especially in predominantly low-income districts. **New Leaders recommends funding EIR at a level of $180 million, the amount requested by the Administration.**

In addition, the Teacher and School Leader Incentive Program (TSLIP) provides for the development and implementation of sustainable, performance-based compensation systems for teachers, principals, and other personnel in high-need schools in order to increase educator effectiveness and student achievement. This program has been instrumental in helping schools and districts move from a pay system based primarily on seniority to one that focuses on student outcomes. **New Leaders recommends at least $250 million in funding for TSLIP in FY2017—the amount requested by the Administration—and a continued focus on improving broader human capital systems in schools.**

Finally, the Supporting Effective Educator Development program (SEED) makes grants to national nonprofit organizations for projects that recruit, select, prepare, or provide professional development activities for teachers or principals. The importance of recruiting, training, and

---

retaining effective principals and other school leaders cannot be overstated. School leaders account for 25 percent of a school's effect on a student achievement,[1] and 97 percent of teachers say that the principal is responsible for determining whether a school can attract and retain great teachers.[2] It is imperative that we make the necessary investments in evidence-based programs that help develop and retain outstanding leaders. **New Leaders recommends that SEED be funded at $100 million in FY2017, as recommended in the Administration's budget request.**

Thank you for the opportunity to provide the views of New Leaders on the FY2017 appropriations. If you would like to discuss our recommendations, please do not hesitate to contact our Chief Policy Officer, Jackie Gran, at policyteam@newleaders.org.

[1] Leithwood, K., Louis, K. S., Anderson, S., & Wahlstrom, K. (2004). *How Leadership Influences Student Learning.* New York, NY: Wallace Foundation.
[2] Scholastic Inc. (2012). *Primary Sources: America's Teachers on the Teaching Profession.* New York, NY: Scholastic and the Bill and Melinda Gates Foundation.

TESTIMONY OF

Harry P. Selker, MD, MSPH
Dean, Tufts Clinical and Translational Science Institute
Executive Director, Institute for Clinical Research and Health Policy Studies

ON BEHALF OF

The Coalition for Clinical and Translational Science (CCTS), which includes
Association for Clinical and Translational Science, 2025 M St NW, # 800, Washington, DC 20036;
The Clinical Research Forum, 6701 Democracy Blvd, # 300, Bethesda, MD 20817;
and other stakeholders

REGARDING

Fiscal Year (FY) 2017 appropriations for clinical and translational research, and research training and career development programs funded annually through the Labor, Health and Human Services, Education, and Related Agencies (L-HHS) Appropriations Bill

SUBMITTED TO

The House Committee on Appropriations
Subcommittee on Labor, Health and Human Services,
Education, and Related Agencies

ON

The 15th Day of April, 2016

FY 2017 Appropriations Recommendations

- **CCTS joins the broader medical research and public health community in asking Congress to provide NIH with $34.5 billion, an increase of $2.4 billion over FY 2016, with proportional increases for various Institutes and Centers.**
    - Please provide the **National Center for Advancing Translational Sciences** (NCATS) with $736.6 million in FY 2017 (a proportional 7.47% increase).
    - Please continue to support and provide meaningful funding increases for the **Clinical and Translational Science Awards (CTSA)** program at NCATS and oppose the diversion of designated CTSA funds by NCATS to non-CTSA activities at CTSA institutions.
    - Please continue to support and provide meaningful funding increases for the **Institutional Development Awards (IDeA)** program at the National Institute for General Medical Sciences and the **Research Centers in Minority Institutions (RCMI)** program at the National Institute on Minority Health and Health Disparities.

- **CCTS joins the broader medical research community in asking Congress to restore funding for the Agency for Healthcare Research and Quality (AHRQ) to the FY15 level of $363.7 million (an increase of $29.7 million).**
    - Please continue to support research training and career development activities at AHRQ, specifically established "K" and "T" award mechanisms.

Chairman Cole, Ranking Member DeLauro, and distinguished members of the Subcommittee, thank you for your time and your consideration of the priorities of the clinical and translational research community as you work to craft the FY 2017 L-HHS Appropriations Bill. Before I begin, the community would like to thank you for your past support of the full spectrum of medical research, including the $2.1 billion funding increase provide to NIH in FY 2016.

ABOUT THE COALITION FOR CLINICAL AND TRANSLATIONAL SCIENCE

CCTS is the unified voice of the clinical and translational science research community. CCTS is a nationwide, grassroots network of dedicated individuals who work together to educate Congress and the Administration about the value and importance of federal clinical and translational research and research training and career development activities. The Coalition includes the Nation's leading health research institutions. CCTS's goals are to ensure that the full spectrum of medical research is adequately funded, the next generation of researchers is well-prepared, and the regulatory and public policy environment facilitates ongoing expansion and advancement of the field of clinical and translational science.

Association for Clinical and Translational Science (ACTS)

ACTS supports investigations that continually improve team science, integrating multiple disciplines across the full translational science spectrum: from population based and policy research, through patient oriented and human subject clinical research, to basic discovery. Our goal is to improve the efficiency with which health needs inform research and new therapies reach the public.

ACTS is the academic home for the disciplines of research education, training, and career development for the full spectrum of translational scientists. Through meetings, publications, and collaborative efforts, ACTS will provide a forum for members to develop, implement, and evaluate the impact of research education programs.

ACTS provides a strong voice to advocate for translational science, clinical research, patient oriented research, and research education support. We will engage at the local, state, and federal levels and coordinate efforts with other professional organizations.

ACTS will promote investigations and dissemination of effective models for mentoring future generations of translational scientists. Through collaborative efforts, ACTS will provide a forum for members to share studies, promote best practices, and optimize professional relationships among trainees and mentors.

The Clinical Research Forum (CRF)

CRF was formed in 1996 to discuss unique and complex challenges to clinical research in academic health centers. Over the past decade, it has convened leaders in clinical research annually and has provided a forum for discussing common issues and interests in the full spectrum of research. Through its activities, the Forum has enabled sharing of best clinical practices and increasingly has played a national advocacy role in support of the boarder interests and needs of clinical research.

Governed by a Board of Directors constituted of clinical researchers from thirteen member institutions, CRF has grown to sixty members from academia, industry, and volunteer health organizations. CRF engages leaders in the clinical research enterprise including leaders from government, foundations, other not-for-profit organizations, and industry in addressing the challenges and opportunities facing the clinical research enterprise.

Parallel with our widening focus upon the broad needs of the entire national clinical research enterprise, CRF is committed to working in those areas where it is uniquely positioned to have a significant impact. Collaboration with other organizations with similar goals and synergizing with their efforts strengthens all approaches to the issues facing clinical research.

NATIONAL INSTITUTES OF HEALTH

This nation has a proud history as a global leader in medical research and biotechnology. This leadership has provided our country with cutting-edge patient care, high-quality jobs, and meaningful economic growth. The Milliken Institute recently calculated that every dollar invested in NIH returns about a $1.70 in economic output in the short term and as much as $3.20 long-term. Crucially, through a robust external research program, NIH resources flow out to the states where the benefit of the funding infusion is felt on the local level.

NIH's impact on public health has been profound. Conditions once considered a death-sentence can now be managed, survival rates for patients with life-threatening diseases have increased dramatically, and additional innovative therapies and diagnostic tools come to market each year. NIH has been successful, but much more can be done. Please provide NIH with at least $34.5 billion in FY 2017 so ongoing research projects can be adequately supported and new research activities can be initiated.

THE FULL SPECTRUM OF MEDICAL RESEARCH

Clinical and Translational Science Awards (CTSAs)

Thank you for providing CTSA's with $500 million in FY 2016. We hope you will provide a proportional increase of nearly 7% for CTSAs in FY 2017. Further, we hope funds appropriated by Congress for CTSAs continue to be used by NCATS for infrastructure and core long-term activities at CTSA sites.

NIH's CTSA Program, which is housed within the National Center for Advancing Translational Sciences (NCATS), is transforming the efficiency and effectiveness of clinical and translational research. Since its establishment with a handful of centers in 2006, the CTSA program has expanded to 62 of the leading medical research institutions located across the country. These centers are linked together and work in concert to improve human health by energizing the research and training environment to innovate and enhance the quality of clinical and translational research.

Recently, based on a recommendation by your Committee, the Institute of Medicine (IOM) released a review of the CTSA program. The report entitled, *The CTSA Program at NIH:*

Opportunities for Advancing Clinical and Translational Research, spoke favorably of the CTSA effort and made the following recommendations to improve the program:

(1) Strengthen NCATS leadership of the CTSA program, (2) reconfigure and streamline the CTSA Consortium, (3) build on the strengths of individual CTSAs across the spectrum of clinical and translational research, (4) formalize and standardize evaluation processes for individual CTSAs and the CTSA Program, (5) advance innovation in education and training programs, (6) ensure community engagement in all phases of research, (7) strengthen clinical and translational research relevant to child health.

CCTS supports the recommendations of the IOM report and the organization is hopeful these changes will continue to be implemented quickly. Another emerging opportunity is to promote collaboration between CTSAs and all NIH Institutes and Centers. Further, when the CTSA program was authorized, Congress indicated that the consortium would be considered fully-funded when it received an annual appropriation of $750 million.

Institutional Development Awards Program (IDeA)
Thank you for providing the IDeA program with a meaningful funding increase in FY 2016. We hope you will continue to invest in this important program for FY 2017.
The IDeA program broadens the geographic distribution of NIH funding for biomedical research. The program fosters health-related research and enhances the competitiveness of investigators at institutions located in states in which the aggregate success rate for applications to NIH has historically been low. The program also serves unique populations—such as rural and medically underserved communities—in these states. The IDeA program increases the competitiveness of investigators by supporting faculty development and research infrastructure enhancement at institutions in 23 states and Puerto Rico. Through Centers of Biomedical Research Excellence and IDeA Networks for Biomedical Research Excellence, the IDeA program builds important infrastructure and works to advance the field of clinical and translational research.

Research Centers in Minority Institutions (RCMI)
Thank you for providing over $2 million in new funding for RCMI in FY 2016. Please provide another important funding increase for this emerging program in FY 2017.

RCMI develops and strengthens the research infrastructure of minority institutions by expanding human and physical resources for conducting basic, clinical, and translational research. It provides grants to institutions that award doctoral degrees in the health professions or health-related sciences and have a significant enrollment of students from racial and ethnic minority groups that are underrepresented in biomedical sciences. The RCMI program serves the dual purpose of bringing more racial and ethnic minority scientists into mainstream research and promoting minority health research because many of the investigators at RCMI institutions study diseases that disproportionately affect minority populations.

TESTIMONY OF
Dory Kranz
Chief Executive Officer

ON BEHALF OF
The National Alopecia Areata Foundation

REGARDING
Fiscal Year 2017 (FY17) appropriations for medical research and public health programs funded annually througb the Labor, Health and Human Services, Education, and Related Agencies (L-HHS) Appropriations Bill

SUBMITTED TO
The House Committee on Appropriations Subcommittee on Labor, Health and Human Services, Education, and Related Agencies

ON
The 15th Day of April, 2016

THE ASSOCIATIONS'S FY17 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 FY17 funding increase for CDC's National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP).

- **At least $34.5 billion in program level funding for the National Institutes of Health (NIH)**.
    - Proportional funding increases for National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) and the National Center for Advancing Translational Science (NCATS)>

Chairman Cole and distinguished members of the Subcommittee, thank you for your time and your consideration of the priorities of the community of individuals affected by alopecia areata as you work to craft the FY17 L-HHS Appropriations Bill.

ABOUT ALOPECIA AREATA

Alopecia areata is a prevalent autoimmune skin disease resulting in the loss of hair on the scalp and elsewhere on the body. It usually starts with one or more small, round, smooth patches on

the scalp and can progress to total scalp hair loss (alopecia totalis) or complete body hair loss (alopecia universalis).

Alopecia areata affects approximately 2.1 percent of the population, including more than 6.5 million people in the United States alone. The disease disproportionately strikes children and onset often occurs at an early age. This common skin disease is highly unpredictable and cyclical. Hair can grow back in or fall out again at any time, and the disease course is different for each person. In recent years, scientific advancements have been made, but there remains no cure or indicated treatment options.

The true impact of alopecia areata is more easily understood anecdotally than empirically. Affected individuals often experience significant psychological and social challenges in addition to the biological impact of the disease. Depression, anxiety, and suicidal ideation are health issues that can accompany alopecia areata. The knowledge that medical interventions are extremely limited and of minor effectiveness in this area further exacerbates the emotional stresses patients typically experience.

ABOUT THE FOUNDATION

NAAF, headquartered in San Rafael, California, supports research to find a cure or acceptable treatment for alopecia areata, supports those with the disease, and educates the public about alopecia areata. NAAF is governed by a volunteer Board of Directors and a prestigious Scientific Advisory Council. Founded in 1981, NAAF is widely regarded as the largest, most influential, and most representative foundation associated with alopecia areata. NAAF is connected to patients through local support groups and also holds an important, well-attended annual conference that reaches many children and families.

Recently, NAAF initiated the Alopecia Areata Treatment Development Program (TDP) dedicated to advancing research and identifying innovative treatment options. TDP builds on advances in immunological and genetic research and is making use of the Alopecia Areata Clinical Trials Registry which was established in 2000 with funding support from the National Institute of Arthritis and Musculoskeletal and Skin Diseases; NAAF took over responsibility financial and administrative responsibility for the Registry in 2012 and continues to add patients to it. NAAF is engaging scientists in active review of both basic and applied science in a variety of ways, including the November 2012 Alopecia Areata Research Summit featuring presentations from the Food and Drug Administration (FDA) and NIAMS.

THE PATIENT PERSPECTIVE

Vashti Wood – Reston, VA - Alopecia areata is an autoimmune skin disease that impacts millions of Americans, including children. There are currently no FDA-approved therapies indicated to treat alopecia areata and options for affected individuals are extremely limited.

My daughter Sophia, now 9 has, alopecia universalis. She was 1st diagnosed at 5. The 1st time only 40-50% fell out and then grew back and for almost 3 years she had a full head that she combed admiringly many times a day and was a bit obsessed with it for her age but I could understand since she had experienced the loss. About a year ago, I noticed a bald spot the size of a pencil eraser and within days it was the size of a softball, and within weeks every piece of her beautiful hair was gone. One of the hardest things in my life was trying to stay strong for her and not burst into tears every time I looked at her beautiful face and bald head, but I had to be because she was not. It was devastating to her and she cried and cried. A few months ago her eyebrows disappeared and then her eyelashes. She is a vibrant girl and one who had much confidence but this condition has taken that away. I fear for the challenges she has ahead of her, going into puberty and middle school is so stressful and hard even for those that appearance is perfect, that I will do anything and everything in my power to try to find a way to get her hair back. We have put $1,000's of dollars on credit cards this past year for hair accessories, a wig, finding herbs from Australia and having them shipped here to the US, holistic doctor (that insurance doesn't cover at all), and of course dermatologist to no avail unless I would like to put or inject steroids into my 9 year old. No thanks! My husband and I fight over what I am spending and doing and that breaks our daughter's heart even more, but I refuse to not keep trying. I have asked her, do you want me to keep searching, trying things or do you want me to stop? She wants me to keep on finding a way to get her hair back.

I thank you on behalf of myself and of the entire alopecia areata community for consideration of NAAF's requests.

NATIONAL INSTITUTES OF HEALTH

NIH hosts a modest alopecia areata research portfolio, and the Foundation works closely with NIH to advance critical activities. NIH projects, in coordination with the Foundation's TDP, have the potential to identify biomarkers and develop therapeutic targets. In fact, researchers at Columbia University Medical Center (CUMC) have identified the immune cells responsible for destroying hair follicles in people with alopecia areata and have tested an FDA-approved drug that eliminated these immune cells and restored hair growth in a small number of patients. This huge breakthrough lead to NIAMS providing a research grant to the researchers at Columbia to continue this work. In this regard, please provide NIH with meaningful funding increases to facilitate growth in the alopecia areata research portfolio.

ADDITIONAL ACTIVITIES

FDA nominated alopecia areata as a potential condition for specific review through the Patient-Focused Drug Development Initiative (PFDDI). This is because many of the impacts of alopecia areata have to be reported by patients and cannot be measured biologically. While we appreciate that FDA falls under the jurisdiction of the Agriculture Appropriations Subcommittee, we ask that you work with your colleagues on the Appropriations Committee to support this important program. Further, FDA should be encouraged to review all originally-nominated conditions in a timely manner so the PFDDI can continue to move forward.

Additionally, Congresswoman Ileana Ros-Lehtiten is working with the community on introducing a bill that will allow for Medicaid to cover a significant portion of the cost of a cranial prostheses when a doctor deems it medically necessary. The disease can be incredibly debilitating not only physically and psychologically but financially as well. This bill is designed to help lessen the burden placed upon those effected by the disease. Please consider cosponsoring the bill when it is introduced.

Thank you for your time and your consideration of the community's requests.

TESTIMONY OF
Mr. Rino Aldrighetti
President and CEO

ON BEHALF OF
The Pulmonary Hypertension Association (PHA)

REGARDING
Fiscal Year 2017 (FY17) appropriations for medical research and public health programs funded annually through the Labor, Health and Human Services, Education, and Related Agencies (L-HHS) Appropriations Bill

SUBMITTED TO
The House Committee on Appropriations
Subcommittee on Labor, Health and Human Services, Education, and Related Agencies

ON
The 15th Day of April, 2016

THE ASSOCIATIONS'S FY17 L-HHS APPROPRIATIONS RECOMMENDATIONS

- **$7.48 billion in discretionary budget authority for the Health Resources and Services Administration (HRSA).**

- **$7.8 billion in program level funding for the Centers for Disease Control and Prevention (CDC)**, which includes budget authority, the Prevention and Public Health Fund, Public Health and Social Services Emergency Fund, and PHS Evaluation transfers.
  - A proportional FY16 funding increase for CDC's National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP).

- **At least $34.5 billion in program level funding for the National Institutes of Health (NIH).**
  - Proportional funding increases for NIH's National Heart, Lung, and Blood Institute (NHLBI); the National Institute of Child Health and Human Development (NICHD), and the National Center for Advancing Translational Sciences (NCATS).

Chairman Cole and distinguished members of the Subcommittee, thank you for your time and your consideration of the priorities of the pulmonary hypertension community as you work to craft the FY17 L-HHS Appropriations Bill.

ABOUT PULMONARY HYPERTENSION

Pulmonary hypertension (PH) is a disabling and often fatal condition simply described as high blood pressure in the lungs. It affects people of all ages, races and ethnic backgrounds. Although anyone can get PH, there are risk factors that make some people more susceptible.

Treatment and prognosis vary depending on the type of PH. In one type, pulmonary arterial hypertension (PAH), the arteries in the lungs become too narrow to handle the amount of blood that must be pumped through the lungs. This causes several things to happen: a backup of blood in the veins returning blood to the heart; an increase in the pressure that the right side of the heart has to pump against to push blood through the lungs; and a strain on the right side of the heart due to the increased work that it has to do. If this increased pressure is not treated, the right side of the heart can become overworked, become very weak and may possibly fail. Because blood has difficulty getting through the lungs to pick up oxygen, blood oxygen level may be lower than normal. This can put a strain not only on the heart, but also decrease the amount of oxygen getting to the brain.

There is currently no cure for PAH. Twelve treatment options are available to help patients manage their disease and feel better day to day but even with treatment, life expectancy with PAH is limited.

ABOUT THE ASSOCIATION

From simple beginnings – four women who met around a kitchen table in Florida in 1990 – the Pulmonary Hypertension Association has evolved into a community of well over 10,000 pulmonary hypertension patients, caregivers, family members and medical professionals.

As we have grown, we have stayed true to our roots and the vision and ingenuity of our founders: *We continue to work every day to end the isolation that PH patients face, and find a cure for pulmonary hypertension.*

Research
PHA provides grants to promising researchers in the field of pulmonary hypertension. The program fosters new leaders in the field by supporting their interest in PH research and providing them with opportunities to work with mentors and learn new skills. Researchers supported by PHA are looking for new methods for early detection, new treatments to prevent the onset of PH and ultimately a cure for this terrible illness. To date, PHA has leveraged more than $15 million in PH research funding through partnerships with the NIH and others.

Early Diagnosis Campaign
It takes too long for pulmonary hypertension to be diagnosed. The median survival rate without treatment is approximately 2.8 years, making the need to obtain a rapid and accurate diagnosis urgent. Unfortunately, the median duration from symptom onset to a confirmed diagnosis by right heart catheterization is 1.1 years. We are reaching patients too late in the process. Almost three-fourths of patients have advanced PH by the time they are diagnosed, leading more costly treatments and poorer outcomes. For the most advanced cases of PH, a lung or heart-lung

transplant may be the only treatment option. The goal of PHA's Early Diagnosis Campaign is to discover the disease sooner in the early stages. This will allow the start of a treatment regimen that can slow the progression of PH and secure a better life for the patient.

Center Accreditation
The Pulmonary Hypertension Association's Scientific Leadership Council, 28 global leaders in the field of pulmonary hypertension, have spearheaded the PHA-Accredited PH Care Centers (PHCC) initiative. The goal of this initiative is to establish a program for accreditation of centers with special expertise in pulmonary hypertension (PH), particularly pulmonary arterial hypertension (PAH), to raise the overall quality of care and outcomes in patients with this life-threatening disease.

THE PATIENT PERSPECTIVE

The Hicks Family

Carl Hicks is a former Army Ranger and a retired Colonel who led the first battalion into Iraq during the first Iraq war. Every member of his family was touched by pulmonary hypertension after the diagnosis of his daughter Meghan in 1994. I share their story here, in Carl's own words:
We're sorry Colonel Hicks, your daughter Meaghan has contracted primary pulmonary hypertension. She likely has less than a year to live and there is nothing we can do for her.
"Those words were spoken in the spring of 1994 at Walter Reed Army Medical Center. They marked the start down the trail of tears for a young military family that, only hours before, had been in Germany. My family's journey down this trail hasn't ended yet, even though Meaghan's fight came to an end with her death on January 30th, 2009. She was 27.
Pulmonary hypertension (PH) struck our family, as it so often does, without warning. One day, we had a beautiful, healthy, energetic twelve-year old gymnast, the next, a child with a death sentence being robbed of every breath by this heinous disease. The toll of this fight was far-reaching. Over the years, every decision of any consequence in the family was considered first with regards to its impact on Meaghan and her *struggle for breath.*
The investment made by our country in my career was lost, as I left the service to stay nearer my family. The costs for Meaghan's medical care, spread over the nearly fourteen years of our fight, ran well into the seven figures. Meghan even underwent a heart and dual-lung transplant. These challenges, though, were *nothing* compared to the psychological toll of losing Meaghan who had fought so hard for something we all take for granted, a breath of air."

Jessica Armstrong

In 2011, at the age of 29, GS12 Human Terrain Analyst Jessica (Puglisi) Armstrong who was serving in Afghanistan as Department of the Army Civilian began experiencing progressive shortness of breath dizziness, and exercise intolerance.. Jessica reported her symptoms multiple times. The first time she was told that she needed to eat more, then she was diagnosed with dehydration. As her symptoms continued to progress, as is the case with many PH patients, she was told she had asthma and given a series of inhalers . Two months later, she fainted for no apparent reason. A CT scan revealed blood clots in her lungs and Jessica was medically

evacuated to Germany and then to the U.S. Six months after her fist symptoms, she was given a clean bill of health and orders to return to Afghanistan. Not feeling better she sought a second opinion at a civilian hospital where she was finally given a complete work up and diagnosed with chronic thromboembolic pulmonary hypertension.

Jessica had a unique form of PH due to blood clots that can be mitigated with a pulmonary thromboendarterectomy (PTE) – a complex surgery that involves opening the chest cavity and stopping circulation for up to twenty minutes. She describes the surgery, which she underwent at the University of California San Diego, as "more painful than I could ever imagine." She notes that UCSD's PTE program did not begin until 1990 and even now, despite being recognized as the global leaders on this procedure, UCSD has only completed about 3,000 surgeries. The procedure that saved Jessica's life was developed in her lifetime.

Jessica was terminated from Army employment and spent more than $60,000 out of pocket on medical expenses which she has not been able to recoup. She was forced to begin a civilian job just two weeks after her PTE in order to obtain health insurance. Despite this, Jessica is, in many ways, one of the lucky ones. I am glad to report that she is now doing well and serving an integral role at PHA as the Senior Manager of our Early Diagnosis Campaign.

***

Over the past decade, treatment options, and the survival rate, for pulmonary hypertension patients have improved significantly. However, courageous patients of every age lose their battle with PH each day. There is still a long way to go on the road to a cure and biomedical research holds the promise of a better tomorrow.

HEALTH RESOURCES AND SERVICES ADMINISTRATION

Due to the serious and life-threatening nature of PH, it is common for patients to face drastic health interventions, including heart-lung transplantation. Federal organ transplantation activities are coordinated through HRSA. To ensure HRSA can expand its important mission and continue to make improvements in donor lists and donor-matching please provide HRSA with a meaningful funding increase in FY17.

CENTERS FOR DISEASE CONTROL AND PREVENTION

As a result of federal investment in medical research, there are now twelve FDA-approved treatments for PH. The effectiveness of these therapies, however, is dependent on how early a patient can receive an accurate diagnosis and begin treatment. Unfortunately, two-thirds of patients are not diagnosed until PH has reached a late stage. In addition to mitigating the impact of many treatments, late diagnosis puts PH patients in a position to face interventions like heart-lung transplantation and even death. CDC and NCCDPHP have the resources to compliment PHA's own *Sometimes its PH* Early Diagnosis Campaign. Improving public awareness and recognition of PH will not only save lives, it can save the federal healthcare system money. Please provide CDC with meaningful funding increases so the agency can expand its focus into increasingly important and cost-effective areas.

NATIONAL INSTITUTES OF HEALTH

NIH hosts a sizable PH research portfolio. Further, NIH and PHA have a strong track record of working together to advance our scientific understanding of PH. The twelve FDA-approved treatments, more than nearly every other rare disease, are evidence of the return-on-investment from these activities. Please provide NIH with meaningful increases to facilitate expansion of the PH research portfolio so we can continue to improve diagnosis and treatment.

NCATS

The Office of Rare Diseases Research (ORDR), located within NCATS, supports and coordinates rare disease research and provides information on rare diseases to patients, their families, healthcare providers, researchers and the public. In collaboration with other NIH institutes, ORDR funds rare diseases research primarily through the Rare Diseases Clinical Research Network (RDCRN), which supports clinical studies, investigator training, pilot projects, and access to information on rare diseases.

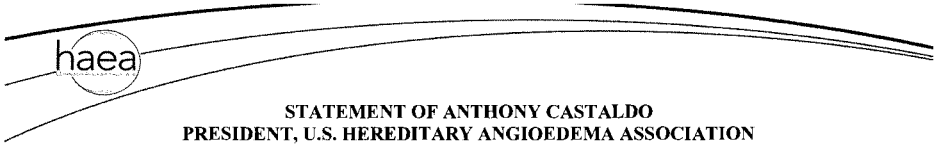
NHLBI

PHA's Research Program has committed more than $15 million for PH research by leveraging partnerships with the National Heart, Lung, and Blood Institute (NHLBI) and the American Thoracic Society (ATS). We have supported 70 promising researchers through four independently reviewed, cutting-edge research programs.

Through a career development award partnership with the National Heart, Lung, and Blood Institute (NHLBI), the Pulmonary Hypertension Association is pleased to provide supplemental funding to individuals who receive an NHLBI Mentored Clinical Scientist Research Career Development Award (K08) or a Mentored Patient-Oriented Research Career Development Award (K23) for research on pulmonary hypertension. The K23 award is focused on patient oriented research where clinicians interact directly with patients in their studies. The K08 award provides support to researchers through supervised research career development in the fields of biomedical and behavioral research, including translational research but whose studies do not include direct interaction with patients.

This program's award recipients are active in the PH community and PHA is proud to have provided support to 11 researchers to date.

The NHLBI-funded Centers for Advanced Diagnostics and Experimental Therapeutics in Lung Diseases Stage II program, which began in FY 2014, provides a mechanism to accelerate the development of therapies for lung diseases, including pulmonary fibrosis and pulmonary arterial hypertension.



STATEMENT OF ANTHONY CASTALDO
PRESIDENT, U.S. HEREDITARY ANGIOEDEMA ASSOCIATION

REGARDING FISCAL YEAR 2017 APPROPRIATIONS
FOR THE NATIONAL INSTITUTES OF HEALTH AND
THE CENTERS FOR DISEASE CONTROL AND PREVENTION

SUBMITTED TO THE HOUSE COMMITTEE ON APPROPRIATIONS
SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES, EDUCATION,
AND RELATED AGENCIES

APRIL 14, 2016

SUMMARY OF FY17 RECOMMENDATIONS

1) Provide $34.5 billion for the National Institutes of Health (NIH)

2) Support the NIH hereditary angioedema research portfolio

3) Encourage the Centers for Disease Control and Prevention (CDC) to advance hereditary angioedema education and awareness

Thank you for the opportunity to present the views of the U.S. Hereditary Angioedema Association (U.S. HAEA) regarding fiscal year 2017 (FY17) funding for the National Institutes of Health (NIH) and the Centers for Disease Control and Prevention (CDC). On behalf of U.S. HAEA, I urge Congress to support hereditary angioedema research and public awareness.

U.S. HAEA is a non-profit patient advocacy organization dedicated to serving the estimated 6,000 HAE sufferers in the U.S. We provide a support network and a wide range of personalized services for patients and their families. We are also committed to advancing clinical research designed to improve the lives of HAE patients and ultimately find a cure.

Hereditary angioedema (HAE) is a painful, disfiguring, debilitating, and potentially fatal genetic disease that occurs in about 1 in 30,000 people. Symptoms include episodes of swelling in various body parts including the hands, feet, face and airway. Patients often have bouts of excruciating abdominal pain, nausea and vomiting that is caused by swelling in the intestinal wall. The majority of HAE patients experience their first attaek during childhood or adolescence. Approximately one-third of undiagnosed HAE patients are subject to unnecessary exploratory abdominal surgery. About 50% of patients with HAE will experience laryngeal edema at some point in their life. This swelling is exceedingly dangerous because it can lead to death by asphyxiation. The historical mortality rate due to laryngeal swelling is 30 percent.

RESEARCH THROUGH THE NATIONAL INSTITUTES OF HEALTH

U.S. HAEA recommends that Congress provide an overall funding level of $34.5 billion for NIH in FY17. In addition. U.S. HAEA urges Congress to include recommendations in accompanying committee reports emphasizing the importance of advancing HAE research per the findings of the October 2014 scientific conference, Expanding Boundaries of our HAE Knowledge.

In October 2014, the NIH National Institute of Allergy and Infectious Diseases (NIAID), the National Center for Advancing Translational Sciences (NCATS), and U.S. HAEA partnered on the state-of-the-science conference, *Expanding Boundaries of our HAE Knowledge*. This conference brought together top HAE researchers as well as other medical researchers across disciplines in order to identify promising avenues for future research. NIH should capitalize on this conference by issuing requests for applications or other opportunities for HAE research based on the findings of the conference.

As a rare disease community, HAE patients are also stakeholders of the Office of Rare Diseases Research (ORDR) and may benefit from programs like the Therapeutics for Rare and Neglected Diseases (TRND) program. U.S. HAEA also urges Congress to robustly support NCATS and the NIH rare disease portfolio in FY17.

CDC PUBLIC AWARENESS AND EDUCATION TO PREVENT HAE DEATHS

In order to prevent deaths, eliminate unnecessary surgeries, and improve patients' quality of life, it is critical that CDC pursue programs to educate the public and medical professionals about HAE in FY17.

HAE patients often suffer for many years and may be subject to unnecessary medical procedures and surgery prior to receiving an accurate diagnosis. Raising awareness about HAE among healthcare providers and the general public will help reduce delays in diagnosis and limit the amount of time that patients must spend without treatment for a condition that could, at any moment, end their lives.

Once diagnosed, patients are able to piece together a family history of mysterious deaths and episodes of swelling that previously had no name. In some families, this condition has come to be accepted as something that must simply be endured. Increased public awareness is crucial so that these patients understand that HAE often requires emergency treatment, and disabling attacks no longer need to be passively accepted. While HAE cannot yet be cured, the use of available treatments can help patients lead a productive life. Education and awareness is needed to reach patients and providers with this message.

Thank you for the opportunity to present the views of the HAE patient community. I hope Congress will support research and education on HAE.

ADDITIONAL MEDICAL RESEARCH ACTIVITIES

For many years (including FY 2016), Congress has included HAE as a condition eligible for study through the Department of Defense Peer-Reviewed Medical Research Program. This opportunity has led to many researchers successfully competing for funding with meritorious research projects that have advanced our scientific understanding of HAE. Further, emerging research has linked HAE episodes to Post-Traumatic Stress Disorder (PTSD) and general anxiety disorder, both of which have a higher prevalence in military service member populations. To capitalize on recent progress and opportunities in this area, please work with your colleagues on the Appropriations Committee to ensure HAE is once again recognized as a condition eligible for study in FY 2017.

TESTIMONY OF
Michael Weamer
President and CEO

ON BEHALF OF
The Marfan Foundation
22 Manhasset Ave.
Port Washington, NY 11050

REGARDING
Fiscal Year 2017 (FY17) appropriations for medical research and public health programs funded annually through the Labor, Health and Human Services, Education, and Related Agencies (L-HHS) Appropriations Bill

SUBMITTED TO
The House Committee on Appropriations
Subcommittee on Labor, Health and Human Services, Education, and Related Agencies

ON
The 15th Day of April, 2016

THE FOUNDATION'S FY17 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 FY17 funding increase for CDC's National Center on Birth Defects and Developmental Disabilities (NCBDDD).

- **At least $34.5 billion in program level funding for the National Institutes of Health (NIH)**.
  - Proportional funding increases for NIH's National Heart, Lung, and Blood Institute (NHLBI); National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS); National Eye Institute (NEI); and National Center for Advancing Translational Sciences (NCATS).

Chairman Cole and distinguished members of the Subcommittee, thank you for your time and your consideration of the priorities of the heritable connective tissue disorders community as you work to craft the FY17 L-HHS Appropriations Bill.

ABOUT MARFAN SYNDROME AND HERITABLE CONNECTIVE TISSUE DISORDERS

Marfan Syndrome

Marfan syndrome is a genetic disorder that affects the body's connective tissue. Connective tissue holds all the body's cells, organs and tissue together. It also plays an important role in helping the body grow and develop properly.

Connective tissue is made up of proteins. The protein that plays a role in Marfan syndrome is called fibrillin-1. Marfan syndrome is caused by a defect (or mutation) in the gene that tells the body how to make fibrillin-1. This mutation results in an increase in a protein called transforming growth factor beta, or TGF-β. The increase in TGF-β causes problems in connective tissues throughout the body, which in turn creates the features and medical problems associated with Marfan syndrome and some related disorders.

Because connective tissue is found throughout the body, Marfan syndrome can affect many different parts of the body, as well. Features of the disorder are most often found in the heart, blood vessels, bones, joints, and eyes. Some Marfan features – for example, aortic enlargement (expansion of the main blood vessel that carries blood away from the heart to the rest of the body) – can be life-threatening. The lungs, skin and nervous system may also be affected. Marfan syndrome does not affect intelligence.

Related Conditions

There are disorders related to Marfan syndrome that can cause people to struggle with some of the same or similar physical problems. Some examples are Loeys-Dietz syndrome, Ehlers-Danlos syndrome, and Familial Thoracic Aortic Aneurysm and Dissection.

Disorders related to Marfan syndrome can also cut lives short, particularly when they go unchecked, and they can deeply affect the quality of life of the individuals and families who must cope with them. Just like people with Marfan syndrome, those affected by related disorders need early and accurate diagnosis to ensure they receive proper care and treatment.

Many of these disorders are genetic conditions that, like Marfan syndrome, cause the aorta (the main blood vessel that carries blood from the heart to the rest of the body) to enlarge, a problem that requires medicine and regular monitoring to determine appropriate treatment. Other features that may overlap with Marfan syndrome include those involving the heart, bones, joints and eyes. Related connective tissue disorders include:

- Loeys-Dietz Syndrome
- Ehlers-Danlos Syndrome
- Familial Thoracic Aortic Aneurysm and Dissection
- Mass Phenotype
- Ectopia Lentis Syndrome
- Beals Syndrome
- Bicuspid Aortic Valve
- Stickler Syndrome
- Shprintzen-Goldberg Syndrome

ABOUT THE FOUNDATION

The Marfan Foundation creates a brighter future for everyone affected by Marfan syndrome and related disorders.

- We pursue the most innovative research and make sure that it receives proper funding.
- We create an informed public and educated patient community to increase early diagnosis and ensure life-saving treatment.
- We provide relentless support to families, caregivers, and healthcare providers.

We will not rest until we've achieved victory—a world in which everyone with Marfan syndrome or a related disorder receives a proper diagnosis, gets the necessary treatment, and lives a long and full life.

THE PATIENT PERSPECTIVE

Krystal Kamire - My journey with Marfan syndrome has been a long and complicated one. I was first tested when I was 19. At that time, the tests were inconclusive. I have some of the features of Marfan syndrome, such as pectus carinatum (pigeon chest), and was very tall and thin, but my measurements were borderline. I had no known family history, and I hadn't developed any serious heart problems. They told me this is not uncommon because I was still young and many people don't begin to have problems until they are older. The doctors couldn't confirm that I had Marfan syndrome, but they also couldn't confirm that I didn't have it. So here I was in limbo, and limbo was where I stayed for a long time.

It's not easy to tell a doctor that you might have Marfan syndrome and have them take you seriously. Honestly, they probably didn't know much more about the condition than I did. Because I wasn't having any luck with doctors, I did the only other thing I could think of: I googled it. That's how I found The Marfan Foundation's website. I signed up to request more information and within a week I had a packet in the mail. But then the most surprising thing happened. I received a phone call from a woman with a local chapter of The Marfan Foundation who reached out to me to help. It might not seem like much, a simple phone call, but it was one of the most influential things to happen to me. I wasn't alone. It is profound to have that realization. I signed up to become a member that very day.

About a year later, I received an email about a meeting in Seattle to form a NW Washington group. That meeting changed my life. I was able to look around the room and see other people with this condition and, once again, saw that I wasn't alone. I met Dr. Byers, my geneticist, that day. There also was a wonderful woman from the Foundation who told me about the Annual Family Conference. She said that they had a medical clinic that allowed you to see the best Marfan specialists in the country for free. I knew then that if I wanted a definite answer, I wouldn't find any better way to get it.

I can honestly say that, if I hadn't received a scholarship to attend the conference, at 33 years old, I still might not have a diagnosis today. Much more important than that, at the conference I

found a community. I met so many people who were like me and, for once, I wasn't the tallest person in the room. And I wasn't the only person who had a pigeon chest. I wasn't the only woman scared to have children. I wasn't the only person there to find answers. I wasn't alone. That, more than anything, is the biggest gift that that this organization has given to me. From now on, I'm not alone. When you spend your whole life trying to pretend that everything is okay because no one will understand, to meet so many people who know exactly what you are going through is life-changing. I found a family within The Marfan Foundation. I know that I can reach out to them at any time and someone will reach back out to me. Just like that first phone call that surprised me so much. I could not begin to express my gratitude to The Marfan Foundation. I only hope that, through this amazing organization, I am able to help someone the way that they have helped me.

CENTERS FOR DISEASE CONTROL AND PREVENTION

People with Marfan syndrome are born with it, but features of the disorder are not always present right away. Some people have a lot of Marfan features at birth or as young children – including serious conditions like aortic enlargement. Others have fewer features when they are young and don't develop aortic enlargement or other signs of Marfan syndrome until they are adults. Some features of Marfan syndrome, like those affecting the heart and blood vessels, bones or joints, can get worse over time.

This makes it very important for people with Marfan syndrome and related disorders to receive accurate, early diagnosis and treatment. Without it, they can be at risk for potentially life-threatening complications. The earlier some treatments are started, the better the outcomes are likely to be.

Knowing the signs of Marfan syndrome can save lives. Our community of experts estimates that nearly half the people who have Marfan syndrome don't know it. CDC and NCBDDD have critical programs that can help improve awareness and recognition of warning signs, which can save lives. Some of these programs include CDC's Million Hearts Campaign and NCBDDD's newborn screening activities.

Additionally, we support the establishment of a new sports screening program to fund awareness in high schools around the country and prevent Marfan syndrome-related thoracic aortic aneurysm and dissection, which claims the lives of young athletes across the country each year. A contemporary example of this need is Isaiah Austin, who was diagnosed with Marfan syndrome just five days before he was supposed to take part in the NBA Draft. Had it not been for the intense testing each potential draftee undergoes as part of the process, Isaiah may never have been diagnosed. He story might have ended by him collapsing on national television or years before while he was playing basketball in college. He is a prime example that more needs to be done. Meaningful funding increases will allow CDC to establish this new activity.

NATIONAL INSTITUTES OF HEALTH

NIH has 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.

National Heart Lung and Blood Institute (NHLBI)
First and foremost, the Foundation applauds NHLBI for the completion of the first clinical trial for Marfan syndrome and for its 10 year support of the GenTAC (Genetically Triggered Thoracic Aortic Aneurysms and Cardiovascular Conditions) registry. To date, the registry has produced numerous publications with data derived from over 3750 subjects. The research derived from this registry covers a wide scope of issues, including surgery, gene discovery, drug therapies outcomes and imaging needs of the community. In FY 15 alone, the following significant results, among many others, have been published utilizing GenTAC data.

- A study was completed investigating the outcomes of calcium channel blockers (CCBs) for Marfan patients when other drug options are not tolerated. CCBs are used for prophylaxis against aortic aneurysm progression, despite limited evidence for their efficacy and safety in the disorder. In recent Marfan animal studies, mice treated with CCBs show accelerated aneurysm expansion, rupture, and premature lethality. Using data collected through the GenTAC registry it was found that aortic tears and aortic repair surgery were more common in patients with Marfan syndrome who had received calcium channel blockers than patients who had been treated with other drugs. These findings suggest that it may be dangerous to treat patients with Marfan syndrome with calcium channel blockers. Additional work will be needed to confirm this risk and to find out if it extends to other similar conditions.

- Using samples from people with autosomal-dominant inheritance of thoracic aortic aneurysms in the GenTAC registry, whole-genome linkage analysis and exome sequencing of was performed. Using this population it was found that rare genetic variants in *MAT2A*, FOXE3 and FBN-1 predispose individuals to thoracic aortic disease. As precision medicine moves forward, incorporation of genomic screening can help predict a person's risk for aortic aneurysm and dissection.

We look to NHLBI to again be a leader in basic, translational and clinical aneurysm research to promote programs which help to facilitate the discovery of novel genes as well as research on identified genes and how their pathways contribute Marfan syndrome and related disorders.

NEI
Ectopia lentis, dislocation of the lens, occurs in up to 60 percent of patients with Marfan syndrome. The central positioning of the lens depends on the zonule of Zinn, a fibrous structure which has fibrillin-1 as a major component. NEI-supported investigators are studying the protein interactions of fibrillin-1 in health and disease in the zonule of Zinn to understand the disease

mechanisms that cause ectopia lentis. It is hoped that this research will provide therapeutic insights to better treat this complication of Marfan syndrome.

National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS)
The Marfan Foundation is proud of its longstanding partnership with NIAMS. Dr. Steven Katz has been a strong proponent of basic research on Marfan syndrome during his tenure as NIAMS director. The Foundation would like to thank the Institute for its 10 years of invaluable support for the program project entitled "Consortium for Translational Research in Marfan Syndrome" which has enhanced our understanding of the disorder and increased the ability to stop the disease progression using a drug-based therapy. The discoveries of fibrillin-1, TGF-beta, and their role in muscle regeneration and connective tissue function were made possible in part through collaboration with NIAMS. NIAMS continues to support critically important research in connective tissues disorders. Unpublished results show dramatic breakthroughs in the underlying mechanisms brought about by a mutation in the fibrillin-1 gene putting Marfan women at extremely high risk during pregnancy. These studies have enabled scientists to identify four medications that can protect against pregnancy-associated aortic tear or rupture in mouse models and these therapies are now being studied for their use in all people with Marfan syndrome. Similarly, scientists have uncovered the potential importance of the interaction between the TGFβ binding complexes and fibrillin-1 microfibrils in the control of detrimental TGFβ signaling involved in aneurysm pathogenesis. Blocking activation of these complexes might represent a potentially novel and specific therapeutic approach to preventing aortic disease. These types of studies indicate the high potential for research to derive novel treatment strategies for Marfan syndrome, and that these insights will prove relevant to other presentations of aortic aneurysm.

In addition to research in Marfan syndrome, we look to NIAMS to help support research in other related connective tissue disorders such as Loeys-Dietz Syndrome, Ehlers Danlos, Shprintzen Goldberg, and Beals syndrome. A mouse model for Loeys-Dietz Syndrome has been established using a mutation in the TGF-β type 2 receptor associated with severe Loeys-Dietz syndrome in humans. The skeletal phenotype observed in the Loeys-Dietz mouse closely resembles the principal structural features of bone in humans with Loeys-Dietz syndrome and establishes this mouse as a valid in vivo model for further investigation of TGF-β receptor signaling in bone. We look to NIAMS to specifically support further bone and skeletal research for this group of related disorders. As always, we hope that NIAMS continues to support as basic, translational and clinical research in the pathogenesis of Marfan and related phenotypes which can lead to novel therapies for these disorders.

Office of Rare Disorder Research at NCATS
The National Center for Advancing Translational Sciences (NCATS) houses ORDR and leads other important activities. In addition to the Rare Disease Clinical Research Consortia, translational treatment development programs hold promise for the heritable connective tissue disorders community.

TESTIMONY OF
Mr. Robert J. Riggs
Chief Executive Officer

ON BEHALF OF
The Scleroderma Foundation (SF)
300 Rosewood Drive, Suite 105
Danvers, MA 01923

REGARDING
Fiscal Year 2017 (FY17) appropriations for medical research and public health programs funded annually through the Labor, Health and Human Services, Education, and Related Agencies (L-HHS) Appropriations Bill

SUBMITTED TO
The House Committee on Appropriations
Subcommittee on Labor, Health and Human Services, Education, and Related Agencies

ON
The 14th Day of April, 2016

THE FOUNDATION'S FY17 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 FY17 funding increase for CDC's National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP).

- **At least $34.5 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 Institute of Diabetes and Digestive and Kidney Diseases (NIDDK); National Institute of Allergy and Infectious Diseases (NIAID); National Center for Advancing Translational Sciences (NCATS).

Chairman Cole 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 FY17 L-HHS Appropriations Bill.

ABOUT SCLERODERMA

Scleroderma, or systemic sclerosis, is a chronic connective tissue disease generally classified as one of the autoimmune rheumatic diseases.

The word "scleroderma" comes from two Greek words: "sclero" meaning hard, and "derma" meaning skin. Hardening of the skin is one of the most visible manifestations of the disease. The disease has been called "progressive systemic sclerosis," but the use of that term has been discouraged since it has been found that scleroderma is not necessarily progressive. The disease varies from patient-to-patient.

It is estimated that about 300,000 Americans have scleroderma. About one third of those people have the systemic form of scleroderma. Since scleroderma presents with symptoms similar to other autoimmune diseases, diagnosis is difficult. There may be many misdiagnosed or undiagnosed cases.

Localized scleroderma is more common in children, whereas systemic scleroderma is more common in adults. Overall, female patients outnumber male patients at a ratio of 4-to-1. Factors other than gender, such as race and ethnic background, may influence the risk of getting scleroderma, the age of onset, and the pattern or severity of internal organ involvement. The reasons for this are still unknown. Although scleroderma is not directly inherited, some scientists feel there is a slight predisposition to it in families with a history of rheumatic or autoimmune diseases. While, scleroderma can develop in every age group from infants to the elderly, its onset is most frequent between the ages of 25 to 55.

Currently, there is no cure for scleroderma. Treatments are based on a patient's particular symptoms. For instance, heartburn can be controlled by medications called proton pump inhibitors or medicine to improve the motion of the bowel. Some treatments are directed at decreasing the activity of the immune system. Due to the fact that there is so much variation from one person to another, there is great variation in the treatments prescribed.

Any chronic disease can be serious. The symptoms of scleroderma vary greatly for each person, and the effects of scleroderma can range from mild to life threatening. The seriousness will depend on which organ systems of the body are affected, and the extent to which they are affected. A mild case can become more serious if not properly treated. Prompt and proper diagnosis and treatment by qualified physicians may minimize the symptoms of scleroderma and lessen the chance for irreversible damage.

ABOUT THE FOUNDATION

The non-profit Scleroderma Foundation is the national organization for people with scleroderma and their families and friends. It was formed January 1, 1998, by a merger between the West Coast-based United Scleroderma Foundation and the East Coast-based Scleroderma Federation. The national office is headquartered in Danvers, Massachusetts. The Foundation has a three-fold mission of support, education, and research.

Support
The Scleroderma Foundation offers the following tools and resources in support of people living with scleroderma and their families:

- A nationwide network of 24 chapters and more than 150 support groups
- A toll-free helpline providing information and referrals to callers
- Educational materials, including a quarterly magazine called "Scleroderma Voice"
- Offer a variety of brochures, booklets and newsletters, along with our informative website

Additionally, the Foundation hosts an annual National Patient Education Conference. The conference offers various educational and networking opportunities for people living with scleroderma, their caregivers, family members and friends. Workshops, panel discussions and other educational sessions are led by the leading scleroderma researchers and healthcare professionals.

Education
As part of our education mission, we not only perform all the functions mentioned above, we also work with our Medical Advisory Board of internationally known scleroderma experts to provide patient education programs as well as education for physician/healthcare professionals.

Research
The Scleroderma Foundation budgets at least $1 million a year for research funding, its single largest budgeted expense. The Scleroderma Foundation takes its fiduciary responsibility to donors very seriously, especially with regard to our research grant program.

ONE FAMILY'S STORY
Cheyenne Cogswell is an eight-year old third-grader living in the poverty-stricken town of Falmouth, Kentucky. Cheyenne was diagnosed at age six with a severe case of systemic scleroderma. The disease has caused kidney failure and significant damage to her digestive system, making it difficult for the body to receive the proper nutrition needed for a growing child. She has undergone several life-saving operations and numerous hospitalizations. Her skin and other internal organs, such as the heart and lungs, are also affected. Cheyenne's treatment first consisted of hospitalization and intense chemotherapy. She continues with daily chemotherapy injections, now given by her mother, to help suppress her immune system and slow the progression of the disease. Cheyenne is being raised by a single mother who has faced extreme consequences from the financial burden created by scleroderma, losing her job in the economic downturn, as well as the family's home. Doctors doubted if Cheyenne would survive beyond her seventh birthday, but she continues to beat the odds. Chronic diseases like scleroderma are unpredictable in their course, and the family – together with their close circle of friends – continues to fight and hope for the best. Their road is uncertain and illustrates why funding for NIH and its research programs are vital to so many people whose lives are impacted by chronic illness such as scleroderma.

CENTERS FOR DISEASE CONTROL AND PREVENTION

Early recognition and an accurate diagnosis of scleroderma can improve health outcomes and save lives. CDC in general and the NCCDPHP specifically have programs to improve public awareness of scleroderma and other rare, life-threatening conditions. Unfortunately, budgetary challenges at CDC have pushed the agency to focus resources on combating a narrow set of "winnable battles." Please increase funding for CDC and NCCDPHP so that the agency can invest in additional, critical education and awareness activities that have the potential to improve health and save lives.

NATIONAL INSTITUTES OF HEALTH

NIH has worked with the Foundation to lead the effort to enhance our scientific understanding of the mechanisms of scleroderma with the shared-goal of improving diagnosis and treatment, and ultimately finding a cure. Since scleroderma is a systemic fibrotic disease it is inexorably linked to other manifestations of fibrosis such as cirrhosis and pulmonary fibrosis that occurs during a heart attack. Scleroderma is a prototypical manifestation of fibrosis as it impacts multiple organ systems. In this way, it is important to promote cross-cutting research across such Institutes as NIAMS, NHLBI AND NIDDK.

Emerging NIH initiatives like the Cures Acceleration Network and the Accelerating Medicines Partnership are creating meaningful opportunities to advance scleroderma research. Please provide NIH with a significant funding increase to the scleroderma research portfolio can continue to expand and facilitate key breakthroughs.

- 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.

ADDITIONAL MEDICAL RESEARCH ACTIVITIES

In recent years, scleroderma has been listed as a condition eligible for study through the Department of Defense (DoD) Peer-Reviewed Medical Research Program (PRMRP). Since FY05, the opportunity for scleroderma researchers to compete for funding through this mechanism led to over $10 million in scleroderma research funding as well as the initiation of meaningful research projects. Military service-associated environmental triggers, particularly silica, solvent, and radiation exposure, are believed to be potential triggers for scleroderma in individuals that are genetically predisposed to it. The scleroderma community urges you to weigh in with your colleagues on the Appropriations Committee to actively work to see that scleroderma is continues to be listed as a condition eligible for study through the PRMRP within the Committee Report accompanying the FY17 Defense Appropriations Bill.

Thank you again for your time and your consideration of the scleroderma community's requests.

National Alliance on Mental Illness

STATEMENT OF MARY GILIBERTI
CHIEF EXECUTIVE OFFICER, NATIONAL ALLIANCE ON MENTAL ILLNESS
TO THE LABOR-HHS-EDUCATION SUBCOMMITTEE
COMMITTEE ON APPROPRIATIONS
U.S. HOUSE OF REPRESENTATIVES
REGARDING FY 2017 FUNDING FOR THE NATIONAL INSTITUTE OF MENTAL HEALTH (NIMH) AND THE SUBSTANCE ABUSE AND MENTAL HEALTH SERVICES ADMINISTRATION (SAMHSA)

APRIL 15, 2016

Chairman Cole and members of the Subcommittee, I am Mary Giliberti, Chief Executive Officer of NAMI (the National Alliance on Mental Illness). I am pleased, today, to offer NAMI's views on the Subcommittee's upcoming FY 2017 bill. NAMI is the nation's largest grassroots advocacy organization dedicated to building better lives for the millions of Americans affected by mental illness.

Through NAMI State Organizations and over 900 NAMI Affiliates across the country, we raise awareness and provide support, education and advocacy on behalf of people living with mental health conditions and their families.

An estimated 1 in 5 people live with a mental health condition in the United States which means more than 43 million Americans are affected. Almost 10 million of those live with a serious mental illness, such as schizophrenia, bipolar disorder, and major depression. People with mental health conditions are our neighbors, our families and ourselves. They work in all sectors of the U.S. economy, from the boardroom to the factory floor, from academia to art.

But, without investment in research and appropriate services and supports, the social and economic costs associated with mental health conditions are tremendous.

Over 42,000 American lives are lost each year to suicide, more than 2 ½ times the number of lives lost to homicide. Suicide is the 2nd leading cause of death for Americans age 15-24 and the 10th leading cause of death for adults.

Mental illness is the 3rd most costly medical condition in terms of overall health care expenditures, behind only heart conditions and traumatic injury. The direct and indirect financial costs associated with mental illness in the U.S. has been estimated to be well over $300 billion annually.

Investing in mental health research and services and supports can make these startling statistics a thing of the past and improve the lives of millions of Americans who live with mental health conditions and their families. NAMI views these investments as the highest priority for our nation and this Subcommittee.

National Institute of Mental Health (NIMH) Research Funding
As a member of the Ad Hoc Group for Medical Research Funding, NAMI supports an overall allocation of no less than $34.5 billion for the National Institutes of Health (NIH). This $2.4 billion increase represents 5% real growth above the projected rate of biomedical inflation and will help ensure that NIH-funded research can continue to improve our nation's health and enhance our competitiveness in today's global information and innovation-based economy. As you know, the President is requesting flat funding for the National Institute for Mental Health (NIMH) for FY 2017 at $1.519 billion. This is extremely disappointing, although the President is requesting an additional $45 million for the BRAIN Initiative. NAMI is extremely grateful for the strong bipartisan support for NIMH that resulted in the $85 million increase for FY 2016. It is critical that this momentum continues in FY 2017.

Supporting the NIMH Strategic Plan
NAMI supports the current five-year NIMH Strategic Plan and its four overarching goals:

- Leveraging progress in genomics, imaging, and cognitive science to define the biology of complex behaviors,
- Building on the concept of mental disorders as neurodevelopmental disorders to chart trajectories and determine optimal times for interventions,
- Using discoveries to focus on new treatments (and eventually cures) based on precision medicine and moving trials into community settings, and
- Increasing the public health impact of NIMH research through improved services that improve access and quality of care.

Accelerating the Pace of Psychiatric Drug Discovery
In NAMI's view, there is an urgent need for new medications to treat serious mental illness. Existing medications can be helpful, but they often have significant limitations; in some cases requiring weeks to take effect, failing to relieve symptoms in a significant proportion of patients, or resulting in debilitating side effects. However, developing new medications is a lengthy and expensive process. Many promising compounds fail to prove effective in clinical testing after years of preliminary research. To address this urgent issue, NAMI is encouraging NIMH to accelerate the pace of drug discovery through an 'experimental medicine' approach to evaluate novel interventions for mental illnesses. This "fast-fail" strategy is designed not only to identify quickly candidates that merit more extensive testing, but also to identify targets in the brain for the development of additional candidate compounds. Through small trials focused on proof-of-concept experimental medicine paradigms, we can make progress to demonstrate target engagement, safety, and early signs of efficacy.

Advancing Services and Intervention Research
NAMI enthusiastically supports the NIMH Recovery After an Initial Schizophrenia Episode (RAISE) Project, aimed at preventing the long-term disability associated with schizophrenia by intervening at the earliest stages of illness. The RAISE Early Treatment Program (RAISE ETP) will conclude this year. The RAISE Connection Program has successfully integrated a comprehensive early intervention program for schizophrenia and related disorders into an existing medical care system. This implementation study is now evaluating strategies for reducing duration of untreated psychosis among persons with early-stage psychotic illness. When individuals with schizophrenia and bipolar disorder progress to later stages of their illness, they become more likely to develop—and die prematurely—from medical problems such as heart disease, diabetes, cancer, stroke, and pulmonary disease than members of the general population. NIMH-funded research is demonstrating progress advancing the health of people with serious mental illness. NIMH needs to advance this research to large-scale clinical trials aimed at reducing premature mortality with people living with serious mental illness.

Investing in Early Psychosis Prediction and Prevention (EP3)
As many as 100,000 young Americans experience a first episode of psychosis (FEP) each year. The early phase of psychotic illness is a critical opportunity to alter the downward trajectory and social, academic, and vocational challenges associated with serious mental illnesses such as schizophrenia. The timing of treatment is critical; short- and long-term outcomes are better when individuals begin treatment close to the onset of psychosis. Unfortunately, the majority of people with mental illness experience significant delays in seeking care—up to two years in some cases. Such delays result in periods of increased risk for adverse outcomes, including suicides, incarceration, homelessness and in a small number of cases, violence.

NIMH-funded research has focused on the prodrome, the high-risk period preceding the onset of the first psychotic episode of schizophrenia. Through the North American Prodrome Longitudinal Study (NAPLS) and other studies focused on early prediction and prevention of psychosis, NIMH has launched the Early Psychosis Prediction and Prevention (EP3) initiative. EP3 is showing promise in detecting risk states for psychotic disorders and reducing the duration of untreated psychosis in adolescents that have experienced FEP.

Advancing Precision Medicine
NAMI supports efforts at NIMH to translate basic research findings on brain function into more person-centered and multifaceted diagnoses and treatments for mental disorders. The Research Domain Criteria (RDoC) is showing promise toward efforts to build a classification system based more on underlying biological and basic behavioral mechanisms than on symptoms. Through continued development, RDoC should begin to give us the precision currently lacking with traditional diagnostic approaches to mental disorders.

Funding for Programs at SAMHSA's Center for Mental Health Services (CMHS)
As noted above, the costs of untreated mental illness to our nation are enormous – as high as $300 billion when taking into account lost wages and productivity and other indirect costs. These costs are compounded by the fact that across the nation states and localities devote enormous resources addressing the human and financial costs of untreated mental illness through law enforcement, corrections, homeless shelters and emergency medical services. This phenomenon of "spending money in all the wrong places" is tragic given that we have a vast array of proven evidence-based interventions that we know work such as assertive community treatment (ACT), supported employment, family psycho-education and supportive housing.

NAMI supports programs at the Center for Mental Health Services (CMHS) at SAMHSA that are focused on replication and expansion of these evidence-based practices that serve children and adults living with serious mental illness. The most important of these programs is the Mental Health Block Grant (MHBG). NAMI is extremely grateful for the $50 million increase for the MHBG that this Subcommittee enacted for FY 2016, boosting funding to $532.57 million.

NAMI strongly supports the doubling of the 5% set aside in the in the MHBG to 10% for early intervention in psychosis. As noted above, the NIMH RAISE study validated the most effective approaches for providing coordinated care for adolescents experiencing FEP. Among these is Coordinated Specialty Care (CSC), a collaborative, recovery-oriented approach that emulates the assertive community treatment approach, combining evidence-based services into an effective, coordinated package. CSC emphasizes shared decision-making—which NAMI strongly supports—with the recipient of services taking an active role in determining treatment preferences and recovery goals.

In 2014, CMHS issued guidance to the states specifying that funding as part of this set aside must be used for those who have developed the symptoms of early serious mental illness, not for "preventive

intervention for those at high risk of serious mental illness." NAMI supports this guidance and we recommend that the Subcommittee continue this 10% set aside for FEP in FY 2017 and beyond. It is critically important for Congress to continue supporting the replication of evidence-based FEP programs in all 50 states. In addition to the MHBG set-aside, NAMI also supports the President's request for a new $115 million state formula grant program for evidence-based early intervention in serious mental illness.

NAMI also recommends the following priorities for CMHS for FY 2017:

- Continuation of the Children's Mental Health program at $117 million,
- Suicide prevention programs under the Garrett Lee Smith Memorial Act at $41.6 million,
- $15 million in funding for states and localities as part of the Assisted Outpatient Treatment (AOT) pilot program as authorized by Congress in Section 224 of P.L. 113-93). NAMI is grateful for the initial allocation of funding made available by the Subcommittee for the AOT pilot for FY 2016. NAMI supports efforts develop a variety of approaches to engaging people with serious mental illness in treatment, including voluntary approaches for engaging people before they reach the point of requiring court-based interventions.

Early Mortality and Serious Mental Illness, Integrating Primary and Behavioral Health Care
The CMHS Primary Behavioral Health Care Integration (PBHCI) program supports community behavioral health and primary care organizations that partner to provide essential primary care services to adults with serious mental illnesses. Because of this program, more than 33,000 people with serious mental illnesses and substance use disorders are screened and treated at 126 grantee sites for diabetes, heart disease, and other common and deadly illnesses in an effort to stem the alarming early mortality rate from these health conditions in this population. NAMI urges the Subcommittee to reject the President's proposal to cut this program by $23.8 million in FY 2017 and fund the PBHCI at $50 million.

Addressing the Needs of Homeless Individuals Living with Serious Mental Illness
NAMI recommends allocating $100 million for services in permanent supportive housing at CMHS. Years of reliable data and research demonstrate that the most successful intervention to solve chronic homelessness is linking housing to appropriate support services. Current SAMHSA investments in homeless programs are highly effective and cost-efficient. However, funding for SAMHSA homeless programs has remained flat for the past four years, often making it difficult for communities to increase the number of homeless households they are serving with the service dollars. As communities are investing additional housing resources into serving high-need homeless populations, Congress should increase investments in services to help those populations address their long-term health related issues.

For the Projects for Assistance in Transition from Homelessness (PATH) program, NAMI recommends $75 million for FY 2017. PATH provides funding for essential outreach to homeless people with serious mental illness and helps them navigate both the homeless and mainstream services systems to get the services they need. PATH-supported programs served over 185,000 people through outreach in fiscal year 2014. Of these, 28% were unsheltered at the time they started receiving PATH services. 64% needed mental health services and 52% had co-occurring substance use disorders. NAMI also recommends an allocation of $10 million from PATH to a demonstration program to create permanent statewide coordination capacity for the SSI/SSDI Outreach, Access and Recovery (SOAR) program. Finally, NAMI urges an allocation of $100 million, the fully authorized level, for services for people experiencing homelessness within the Programs of Regional and National Significance (PRNS) accounts of both SAMHSA's Center for Mental Health Services and Center for Substance Abuse Treatment.

Conclusion
Chairman Cole, thank you for the opportunity to share NAMI's views on the Labor-HHS-Education Subcommittee's FY 2017 bill. NAMI's members across the country thank you for your leadership on these important national priorities.

Robert Clapp

Assistant Director of Specialized Services

Center for Independent Living of Central Pennsylvania

I am writing to support the National Council on Independent Living's request for Congress to reaffirm your commitment to the more than 57 million Americans disabilities by increasing funding in the HHS appropriations for Centers for Independent Living (CILs). I am asking that you increase funding by $200 million, for a total of $301 million for the Independent Living line item in FY 2017.

CILs are cross-disability, non-residential, community-based, nonprofit organizations that are designed and operated by individuals with disabilities. CILs are unique in that they are directly governed and staffed by people with all types of disabilities, including people with mental, physical, sensory, cognitive, and developmental disabilities. Each of the 365 federally funded centers provides five core services: information and referral, individual and systems advocacy, peer support, independent living skills training, and transition services, which were added with the passage of the Workforce Innovation and Opportunity Act (WIOA). From 2012-2014, CILs provided the core services to nearly 5 million people with disabilities, and provided additional services such as housing assistance, transportation, personal care attendants, and employment services to hundreds of thousands of individuals. During this same period, prior to transition being added as a core service, CILs transitioned 13,030 people with disabilities from nursing homes and other institutions into the community.

Transition services were added as a fifth core service with the 2014 reauthorization of the Rehabilitation Act within the Workforce Innovation and Opportunity Act. Transition services include the transition of individuals with significant disabilities from nursing homes and other institutions to home and community-based residences with appropriate supports and services, assistance to individuals with significant disabilities at risk of entering institutions to remain in the community, and the transition of youth with significant disabilities to postsecondary life. This core service is vital to achieving full participation for people with disabilities.

Every day, CILs are fighting to ensure that people with disabilities gain and maintain control over our own lives. We know that this cannot occur when people reside in institutional settings. Opponents of deinstitutionalization say that allowing people with disabilities to live in the community will result in harm. We know that the 13,030 people with disabilities who CILs successfully transitioned out of nursing homes and institutions from 2012-2014 prove otherwise. Additionally, when services are delivered in an individual's home, the result is a tremendous cost savings to Medicaid, Medicare, and states. Community-based services enable people with disabilities to become less reliant on long-term government supports, and they are significantly less expensive than nursing home placements. We are grateful that Congress demonstrated their understanding and support for community-based services when WIOA was passed and transition was added as a fifth core service.

Since transition services were added as a core service, the need for funding is critical. Moreover, CILs need additional funding to restore the devastating cuts to the Independent Living program, make up for inflation costs, and address the increased demand for independent living services. In

2016, the Independent Living Program is receiving $2.5 million less in funding than it was in 2010. It is simply not possible to meet the increasing demand for services and effectively provide transition services without additional funding. Increased funding should be reinvested from the billions currently spent to keep people with disabilities in costly Medicaid nursing homes and institutions and out of mainstream society.

Centers for Independent Living play a crucial role in the lives of people with disabilities, and work tirelessly to ensure that people with disabilities have a real choice in where and how they live, work, and participate in the community. Additionally, CILs are an excellent service and a bargain for America, keeping people engaged with their communities and saving taxpayer money. NCIL is dedicated to increasing the availability of the invaluable and extremely cost-effective services CILs provide, and they have submitted written testimony with a similar request. I strongly support NCIL's testimony.

NACCHO
National Association of County & City Health Officials
The National Connection for Local Public Health

Statement of the
NATIONAL ASSOCIATION OF COUNTY AND CITY HEALTH OFFICIALS
1100 17th St. NW, 7th Floor
Washington, DC 20036

Submitted for the record to the Subcommittee on Labor, Health and Human Services and Education, Committee on Appropriations
United States House of Representatives

FY2017 Appropriations for Programs at the Department of Health and Human Services

Contact: *Eli Briggs, NACCHO Senior Government Affairs Director*
202-507-4194/ebriggs@naccho.org

The National Association of County and City Health Officials (NACCHO) is the voice of the 2,800 local health departments across the country. City, county, metropolitan, district, and tribal health departments work to ensure the public's health and safety. On behalf of local health departments, NACCHO submits the following requests:

Emergency Funding for Zika Virus

NACCHO urges Congress to provide emergency supplemental funding to respond to the Zika virus without delay. Recently the Centers for Disease Control and Prevention (CDC) announced that evidence links the virus to serious health impacts, miscarriages and birth defects. With this funding, state and local health departments would be supported by CDC with increased virus readiness and response capacity; enhanced laboratory, epidemiology and surveillance capacity in at-risk areas to reduce the opportunities for Zika transmission and surge capacity through rapid response teams to limit potential clusters of Zika virus in the United States. In addition funds are needed to restore $44 million cut from CDC public health emergency preparedness grants (PHEP) in FY2016 to transfer to the agency's Zika response.

Public Health Emergency Preparedness – CDC

NACCHO urges the Subcommittee to provide $675 million for Public Health Emergency Preparedness (PHEP) in FY2017. Recent events include the threat of infectious diseases like Zika and mumps, as well as severe and frequent weather events causing natural disasters. Sustained funding to support local preparedness and response capacity is needed to make sure that every community is prepared for disaster. CDC cut $44 million from PHEP grants in FY2016 to transfer to the agency's response to the Zika virus. More than 55% of local health departments rely solely on federal funding for emergency preparedness.

Hospital Preparedness Program – Assistant Secretary for Preparedness and Response (ASPR)

The Hospital Preparedness Program (HPP) supports regional health care coalitions (HCCs), which are formal collaborations among health care and public health organizations. This program provides vital grant funding to states and four directly funded cities to build healthcare coalitions that enhance regional and local hospital preparedness and improve overall surge capacity. NACCHO urges Congress to begin restoring HPP funding that was cut by a third ($104 million) in FY2014 by increasing it to $300 million in FY2017.

Medical Reserve Corps - ASPR

In 2002, the Medical Reserve Corps (MRC) was created after the terrorist attacks of 9/11 to establish a way for medical, public health, and other volunteers to address local health and preparedness needs. These highly skilled volunteers include doctors, dentists, nurses, pharmacists, and other community members. The program is comprised of 200,000 volunteers

enrolled in 1,000 units in all 50 states and territories. Two-thirds of MRC units are coordinated by local health departments. MRC volunteers fill gaps in routine health services and respond in emergency situations. NACCHO opposed the President's proposed $3 million cut to MRC in FY2016 and requests $11 million in funding in FY2017 to restore funding to the FY2014 level.

Section 317 Immunization Program - CDC

Immunizations continue to be one of the most cost-effective public health interventions. In an effort to prevent and control the spread of infectious diseases, the promotion of vaccinations is needed more now than ever. In 2015, 189 people from 24 states and the District of Columbia were reported to have measles. In 2014, the United States experienced the greatest number of cases since measles elimination was documented in the U.S. in 2000. A strong public health immunization infrastructure is needed to prevent disease in both children and adults. The 317 Immunization Program funds vaccine purchase for at-need populations and immunization program operations, including support for implementing billing systems. According to the CDC, childhood vaccines saved 42,000 lives and prevented 20 million cases of disease with an estimated $10.20 in savings for every $1 invested. NACCHO opposes the President's $50 million cut in FY2017 and supports the $8 million included in the President's budget to build health department capacity for billing to provide reimbursement for services.

Core Infectious Diseases, Including Antibiotic Resistance and Vector-Borne Diseases – CDC

The Core Infectious Disease Program identifies and monitors the occurrence of known and emerging infectious diseases and supports outbreak response. Funding for this program also

addresses antibiotic resistance, emerging infections, healthcare-associated infections, infectious disease laboratories, high-consequence pathogens, and vector-borne diseases. NACCHO is concerned with the erosion of state and local capacity to monitor and address vector-borne diseases such as Zika, Chikungunya, Dengue, and West Nile and thus supports the President's $40 million increase ($428 million total) for FY2017.

Prescription Drug (Opioid) Overdose Prevention – CDC

The Prescription Drug (Opioid) Overdose Prevention Program provides states with the funding for prescription drug abuse and overdose prevention programs in the hardest hit communities, enhances prescription drug monitoring programs (PDMPs), implements insurer and health system interventions to improve prescribing practices, and collaborates with a variety of state entities such as law enforcement. The number of deaths due to opioid overdose has increased to 78 people per day. Thus, NACCHO supports the President's $10 million increase ($80 million total) for FY2017 and urges CDC to ensure that these funds reach local communities in order to respond effectively to this epidemic.

Childhood Lead Poisoning Prevention – CDC

NACCHO supports the restoration of childhood lead prevention funding to the FY2010 level of $35 million in FY2017. Lead poisoning remains a major public health threat today as over half a million children have blood levels high enough to threaten their health. This program provides funding for 29 state and 6 city health departments to identify families with harmful exposure to lead, track incidence and causes, inspect homes and remove environmental threats, connect

children with appropriate services, and provide education to health care providers as well as the public. The recent tragedy of lead poisoning in Flint, MI and other communities around the country emphasizes the need to tackle this continuing public health threat.

Preventive Health and Health Services Block Grant – CDC

NACCHO urges the rejection of the President's proposed elimination (a cut of $160 million) of the Preventive Health and Health Services (PHHS) Block Grant. The PHHS Block Grant gives states the autonomy and flexibility to solve state problems and support similar issues in local communities, while still being held accountable for demonstrating local, state, and national impact of their investments. NACCHO also asks for report language asking the CDC to expand grantee reporting requirements to include the amount of money going to local communities.

Prevention and Public Health Fund (HHS)

In FY2017, NACCHO requests $1 billion for the Prevention and Public Health Fund (PPHF), a dedicated federal investment in programs that prevent disease at the community level, and continued allocation of the PPHF through the annual appropriations process. The PPHF supports core public health programs such as immunization, chronic disease prevention, lead poisoning prevention, and early and rapid detection of diseases and injury.

In conclusion, thank you for your attention to these recommendations for programs that protect the public's health and safety.

Alliance for Aging Research
Testimony on FY 2017 National Institutes of Health Appropriations

Submitted to:
House Subcommittee on Labor, Health, and Human Services Education and Related Agencies

Submitted by:
Cynthia Bens, Vice President Public
Alliance for Aging Research
1700 K Street NW, Suite 740
Washington, DC 20006
Phone: (202) 293-2856
Fax: (202) 255-8294
Email: cbens@agingresearch.org

April 15, 2015

Chairman Cole, Ranking Member Delauro, and members of the subcommittee, for 30 years the nonprofit Alliance for Aging Research, has advocated for policies that will accelerate the pace of scientific discoveries and their application to improve the universal experience of aging and health. We support increased federal funding of aging research by the National Institutes of Health (NIH), through the National Institute on Aging (NIA) and other NIH institutes and centers. The Alliance for Aging Research appreciates the opportunity to submit testimony highlighting the important role the NIH plays in facilitating medical research activities related to aging and the need for sustained federal investment to advance scientific discoveries to keep aging Americans healthier longer. When considering the rapid aging of America and the resources the federal government devotes to Medicare and other healthcare services for age-related diseases, we find it prudent to increase appropriated spending on aging research. Considering the unique funding challenges facing the NIA, and the range of promising scientific opportunities in the field of aging research, **the Alliance for Aging Research recommends an additional $500 million in the FY 2017 NIH budget to support biomedical, behavioral, and social sciences aging research efforts at the NIH and a minimum increase of $400 million in Alzheimer's disease and related dementias research.** To ensure that overall research progress at the NIH continues, **the Alliance for Aging Research endorses the Ad Hoc Group for Medical Research recommendation that the NIH be funded at $34.5 billion in FY 2017. We further urge the committee to include report language requesting that the U.S. Secretary of Health and Human Services establish an Interagency Geroscience Research Coordination Committee (IGRCC)** comprised of representatives from the NIH, FDA and other designated agencies to identify and direct grants for new geroscience research; **and, to provide $1 million to administer the activities of the IGRCC and $5 million in grant-making authority to advance aging research priorities.**

The NIA leads the national scientific effort to understand the nature of aging and to extend the healthy, active years of life. Congress established the NIA in 1974 with the mission of conducting and supporting genetic, biological, clinical, behavioral, social, and economic

researched related to the aging process, diseases and conditions associated with aging, and needs of older Americans; developing research and clinician-scientists for research and aging; and disseminate information about aging and advances in research with the scientific community, healthcare providers, and the public. These following projects highlight some of the important work directed by the NIA:

- The Biology of Aging Program is a trans-NIH initiative, coordinating with the Nathan Shock Centers of Excellence, to support translational research at the individual and community level. Under this umbrella, the Interventions Testing Program seeks to identify compounds that extend median and/or maximal life span in both mammal and non-mammalian organisms.
- The Behavioral and Social Research Program conducts longitudinal studies focusing on trends in late-life disability and on the influences of behavioral, psychological, and social factors in mid-life on age-related variations in health and well-being. Major programs include initiatives to stimulate research on mid-life adults informing efforts to optimize health and well-being, prevent illness and disability in later years, and potentially reverse the negative impact of early life adversity on later life health.
- The Geriatrics and Clinical Gerontology Program is studying how early life factors influence health and diseases as people age. The program also plans and administers clinical trials for age-related conditions and is conducting an on-going initiative to identify behavioral interventions with a high potential impact to improve health outcomes for individuals with three or more chronic conditions.
- The Neuroscience Program seeks to expand knowledge on the aging nervous system to allow improvement in the quality of life of older people. The program supports a national network of Alzheimer's disease centers to translate research advances into improved diagnosis and care of Alzheimer's disease patients.
- The Accelerating Medicines Partnership (AMP) is a collaboration between the NIH and 10 pharmaceutical company partners to identify and characterize biomarkers and targets of intervention for Alzheimer's disease, type 2 diabetes, and autoimmune disorders, rheumatoid arthritis, and systemic lupus erythematosus.
- The Healthy Aging in Neighborhood of Diversity across the Life Span (HANDLS) is a 20-year project within the NIA Intramural Research Program to examine the influences of race and socioeconomic status on the development of age-related health disparities in Baltimore.
- The NIA has partnered with Patient-Centered Outcomes Research Institute (PCORI) on an intervention study testing individually tailored strategies for falls prevention in older adults.

The NIA's mission becomes ever more urgent as the American population ages. Older Americans now make up the fastest growing segment of the population. According to the U.S. Census Bureau, the number of Americans aged 65 and older is expected to double between 2010 and 2050 to 88.5 million; the number of Americans aged 85 and older is expected to triple in the same time period. The impact this will have on the U.S. healthcare system is profound. As the American population ages, the number of Americans living with chronic diseases skyrockets.

The influx of Americans living with the chronic diseases of aging threatens to overwhelm the U.S. health care system. According to the Centers for Medicare & Medicaid Services, in 2011 approximately 23 percent of beneficiaries had four to five chronic diseases associated with aging. This increase of people living with multiple chronic disease is a large contributing factor to the Congressional Budget Office projecting total spending on healthcare to increase by 25 percent of the U.S. GDP by 2025. Streamlining delivery and eliminating unneeded care will not sufficiently contain the costs of caring for the chronic diseases of geriatric populations. To effectively solve this problem, we must increase federal resources to understand the biology of aging. Research to better understanding the aging process and its underlying relationship to chronic disease could help Americans live longer and more productive lives while greatly alleviating much of the burden to the healthcare system. Scientists studying aging are in general agreement that there is a strong likelihood the pace of aging can be slowed. Closing the gap between the promises of basic research into aging and the clinical application of this research will require considerable focus and investment.

An increase in funding for aging research is urgently needed to enable scientists to capitalize on the field's recent exciting discoveries. The Alliance for Aging Research, has led the Healthspan Campaign—an awareness campaign to educate the public and policymakers about the need to focus and adequately fund basic research into the underlying processes of aging—that if targeted can extend a person's healthy years of life. In addition to increased resources, we believe that the field could benefit from the creation of a trans-agency coordinating committee that could improve the quality and pace of research that advances the understanding of aging, its impact on age-related diseases, and the development of interventions to extend human healthspan. Throughout the first half of 2012 the Alliance and its Healthspan Campaign partners met with the leadership of the NIA, the National Institute of Neurological Diseases and Stroke (NINDS), the National Institute of Arthritis Musculoskeletal and Skin Diseases (NIAMS), the National Institute of Diabetes Digestive and Kidney Diseases (NIDDK), the National Heart Lung and Blood Institute (NHLBI), and the National Cancer Institute (NCI). These meetings led to the establishment of the Trans-NIH GeroScience Interest Group (GSIG), a group seeking to discover common risks and mechanisms behind age-related diseases and conditions. Twenty-one of the 27 institutes and centers at the NIH are now working on the GSIG. The regular meetings, quarterly seminars, and the recommendations from the "Advances in Geroscience: Impact on Healthspan and Chronic Disease Summit" have identified multiple opportunities for collaboration. Funding these research opportunities can reduce the burden of a "Silver Tsunami" of age-associated chronic diseases. We urge the committee to include report language requesting that the U.S. Secretary of Health and Human Services establish an Interagency Geroscience Research Coordination Committee (IGRCC) comprised of representatives from the NIH, FDA and other designated agencies to identify and direct grants for new geroscience research; and, to provide $1 million to administer the activities of the IGRCC and $5 million in grant-making authority to advance aging research priorities.

NIA leads the federal effort on researching Alzheimer's disease, receiving roughly 70 percent of NIH Alzheimer's disease research funding. As many as five million Americans aged 65 years and older are living with Alzheimer's disease, with 13.2 million anticipated by 2050. The national cost of caring for individuals with Alzheimer's disease is estimated at $100 billion

annually. To address the problem, the NIA has a comprehensive research agenda to understand the disease, spanning from basic neuroscience through translational research and clinical applications. The NIA supports treatment trials that aim to slow the disease or alleviate its symptoms, such as last year's discovery that the anti-depressant citalopram may be a safer and more effective treatments for disruptive agitation in Alzheimer's disease than currently used treatments.

The exponential increase in computer processing power has strengthened the NIA's efforts to study Alzheimer's disease. These new technologies allow researchers to generate and analyze enormous data sets with the aim of identifying risk and protective genes for Alzheimer's disease. This has led to the Alzheimer's disease Sequencing Project (ADSP), a collaborative effort between the NIA and the National Human Genome Research Institute working to identify genomic variants contributing to the development and protecting against the development of Alzheimer's disease. The NIA is also using the Accelerating Medicines Partnership (AMP) to incorporate an expanded set of biomarkers into three ongoing trials designed to delay or prevent Alzheimer's disease and determine their usefulness in tracking disease progression and treatment responsiveness. These trials will be ongoing from 2017 to 2020. AMP also supports large-scale systems biology analyses using data from 2,500 brains at different stages of Alzheimer's disease to build predictive models of the disease. All of the data from this initiative is shared with the public.

However, despite the NIH's exciting work on Alzheimer's disease, the current level of funding the NIH receives is insufficient to meet the National Plan to Address Alzheimer's disease's goal of developing effective treatment modalities to treat or cure Alzheimer's disease by 2025. To meet this goal, **we support an increase of at least $ 400 million for Alzheimer's disease and related dementia research**. This would put the NIH-wide dementia research budget at $1.34 billion in FY 2017. Furthermore, the NIA's current budget does not reflect the tremendous responsibility it has to meet the health research needs of America's aging population. When adjusting for inflation, the NIA's budget has decreased more than 20 percent since 2003. **An increase of $500 million will allow the NIH to capitalize on the potential transformational gains in aging research**. Few, if any, investments have a greater potential return on investment for public health. **The Alliance for Aging Research recommends that overall NIH funding be increased to $34.5 billion in FY 2017. We also support a minimum $500 million increase over FY 2016 enacted levels for aging research across the NIH** that will accelerate progress toward preventing, treating, and slowing the progression, or even possibly curing conditions related to aging. We would also be remiss not to acknowledge the Subcommittee's significant increase for the NIH and Alzheimer's disease and related dementia research in FY 2016. We truly appreciate your prioritization of the critical work conducted at the NIH and ask for your ongoing support.

Mr. Chairman, thank you for the opportunity to present testimony and elucidate on the challenges posed by the aging population. Our organization will gladly provide additional information and answer questions upon request.

Statement by the Ad Hoc Group for Medical Research on
FY 2017 Appropriations for the National Institutes of Health
Submitted for the record on April 15, 2016, to the
Subcommittee on Labor, Health and Human Services, Education and Related Agencies
Committee on Appropriations
United States House of Representatives

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

The Ad Hoc Group is deeply grateful to the Subcommittee for its long-standing and bipartisan leadership in support of NIH, as demonstrated most recently by the $2 billion increase provided in the fiscal year (FY) 2016 omnibus spending bill. We believe that science and innovation are essential if we are to continue to meet current and emerging health challenges, improve our nation's health, and sustain our leadership in medical research.

If this nation is to continue to accelerate the development of life-changing cures, pioneering treatments, and innovative prevention strategies, it is essential to sustain predictable increases in the NIH budget.

The Ad Hoc Group recommends that Congress appropriates at least $34.5 billion through the Labor-HHS-Education spending bill for FY 2017. This $2.4 billion increase represents 5 percent real growth above the projected rate of biomedical inflation, and will help ensure that NIH-funded research can continue to improve our nation's health and enhance our competitiveness in today's global information and innovation-based economy.

We share the bipartisan enthusiasm in Congress for the potential that NIH-supported research holds in improving the health and well-being of all Americans. We look forward to working with appropriators to secure an increase of 5 percent real growth in FY 2017 for NIH as the next step to ensuring stability in the nation's research capacity over the long term. We also stand ready to work with authorizers on unique mechanisms to take full advantage of the exceptional scientific opportunities now available and to meet current and emerging health challenges.

NIH: A Public-Private Partnership to Save Lives and Provide Hope

The partnership between NIH and America's scientists, medical schools, teaching hospitals, universities, and research institutions is a unique and highly-productive relationship, leveraging the full strength of our nation's research enterprise to foster discovery, improve our understanding of the underlying cause of disease, and translate this knowledge into the next generation of diagnostics, therapeutics, and other clinical innovations. Nearly 84 percent of the NIH's budget is competitively awarded through more than 55,000 research and training grants to more than 300,000 researchers at over 2,500 universities and research institutions located in every state.

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.

- The death rate for all cancers combined has been declining since the early 1990s for adults and since the 1970s for children. Overall cancer death rates have dropped by about 1.5 percent per year, or nearly 15 percent in total from 2003—2012. Research in cancer immunotherapy has led to the development of several new methods of treating cancer by restoring or enhancing the immune system's ability to fight the disease. As researchers develop new approaches to overcoming tumor avoidance of immune destruction and new methods for identifying antigens on tumor cells that can be targeted most effectively, immunotherapy is becoming an integral part of precision medicine.

- Deaths from heart disease fell 67.5 percent from 1969 to 2013, through research advances supported in large part by NIH. The Framingham Heart Study and other NIH-supported research have identified risk factors for heart disease, such as cholesterol, smoking, and high blood pressure. This work has led to new strategies for preventing heart disease.

- Since 1950, the stroke mortality rate has decreased by 79 percent, due in part to NIH-funded research on treatments and prevention.

- Despite the increasing prevalence of diabetes in the U.S., from 1969 to 2013 the death rate for adults with diabetes declined by 16.5 percent. Between 1990 and 2010, the rates of major diabetes complications dropped dramatically, particularly for heart attacks, which declined by 68 percent, and stroke, which declined by 53 percent. These improvements are due largely to clinical trials supported by NIH. NIH's Diabetes Prevention Program has shown that lifestyle changes, such as diet and physical activity, can lower the risk of developing type 2 diabetes by 58 percent in adults at high risk for the disease.

- Thanks to an unprecedented collaborative effort between NIH and industry, today treatments can suppress HIV to undetectable levels, and a 20-year-old HIV-positive adult living in the United States who receives these treatments is expected to live into his or her early 70s, nearly as long as someone without HIV. Since the mid-1990s, HIV testing and prevention strategies based on NIH research have resulted in a more than 90 percent decrease in the number of children perinatally infected with HIV in the United States.

- In 1960, 26 of every 1,000 babies born in the United States died before their first birthday. By 2013, that rate had fallen to under 6 per 1,000 babies, thanks in large part to NIH research on reducing preterm births, neonatal mortality, and other complications.

- The haemophilus influenza type B (Hib) vaccine has reduced the cases of Hib, once the leading cause of bacterial meningitis in children, by more than 99 percent.

- NIH-supported researchers partnered with a pharmaceutical company to produce a naloxone nasal spray, the first easy-to-use, non-injectable version of a life-saving

treatment for opioid or heroin overdoses. NIH-supported researchers collaborated with the pharmaceutical industry to develop the drug buprenorphine, the first drug for opioid addiction that could be prescribed in a doctor's office instead of requiring daily visits to a clinic.

- As a result of NIH efforts, nearly all infants born in U.S. hospitals in 2010 were screened for hearing loss, allowing them to get hearing aids or cochlear implants during their developmental years when they will be most helpful. Studies have shown that screening and implantation before the age of 18 months allows more than 80 percent of children with hearing loss to join mainstream classes with their normal-hearing peers.

- Deep brain stimulation is used to help relieve symptoms of Parkinson's disease and Obsessive Compulsive Disorder, thanks in part to NIH-funded research, and is currently being tested in other neuropsychiatric conditions, such as treatment-resistant depression and dementia.

- In the mid-1970s, burns that covered even 25 percent of the body were almost always fatal. Today, people with burns covering 90 percent of their bodies can survive. NIH-funded research on wound cleaning, skin replacement, infection control, and other topics has greatly improved the chances of surviving catastrophic burns and traumatic injuries.

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

NIH is the world's premier supporter of merit-reviewed, investigator-initiated basic research. This fundamental understanding of how disease works and insight into the cellular, molecular, and genetic processes underlying life itself, including the impact of social environment on these processes, underpin our ability to conquer devastating illnesses. The application of the results of basic research to the detection, diagnosis, treatment, and prevention of disease is the ultimate goal of medical research. Ensuring a steady pipeline of basic research discoveries while also supporting the translational efforts necessary to bring the promise of this knowledge to fruition requires a sustained investment in NIH.

Sustaining Scientific Momentum Requires Sustained Funding

Despite the increase in FY 2016, over the past decade, NIH has lost more than 22 percent of its budget after inflation, significantly impacting the nation's ability to sustain the scientific momentum that has contributed so greatly to our nation's health and our economic vitality. The leadership and staff at NIH and its Institutes and Centers has engaged patient groups, scientific societies, and research institutions to identify emerging research opportunities and urgent health needs, and has worked resolutely to prioritize precious federal dollars to those areas demonstrating the greatest promise. Sustained predictable increases in NIH funding are needed if we are to continue to take full advantage of these opportunities to accelerate the development of pioneering treatments and innovative prevention strategies.

One long-lasting potential impact of the past decade is on the next generation of scientists, who have seen training funds slashed and the possibility of sustaining a career in research diminished. The continued success of the biomedical research enterprise relies heavily on the imagination and dedication of a diverse and talented scientific workforce. Of particular concern is the challenge of maintaining a cadre of clinician-scientists to facilitate translation of basic research to human medicine. NIH supports many innovative training programs

and funding mechanisms that foster scientific creativity and exploration. Additional funding is needed if we are to strengthen our nation's research capacity, ensure a biomedical research workforce that reflects the racial and gender diversity of our citizenry, and inspire a passion for science in current and future generations of researchers.

NIH is Critical to U.S. Competitiveness

Our country still has the most robust medical research capacity in the world, but that capacity simply cannot weather repeated blows such as persistent below-inflation funding levels and sequestration cuts, which jeopardize our competitive edge in an increasingly innovation-based global marketplace.

Other countries have recognized the critical role that biomedical science plays in innovation and economic growth and have significantly increased their investment in biomedical science. This shift in funding is creating an innovation deficit in the U.S. and raises the concern that talented medical researchers from all over the world, who once flocked to the U.S. for training and stayed to contribute to our innovation-driven economy, are now returning to better opportunities in their home countries. We cannot afford to lose that intellectual capacity, much less the jobs and industries fueled by medical research. The U.S. has been the global leader in medical research because of Congress's bipartisan recognition of NIH's critical role. To continue our dominance, we must reaffirm this commitment to provide NIH the funds needed to maintain our competitive edge.

NIH: An Answer to Challenging Times

The research supported by NIH drives not only medical progress but also local and national economic activity, creating skilled, high-paying jobs and fostering new products and industries. According to a report released by United for Medical Research, a coalition of scientific advocates, institutions and industries, in fiscal year 2011, NIH-funded research supported an estimated 432,000 jobs all across the United States and generated more than $62 billion in new economic activity.

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

Therefore, the Ad Hoc Group for Medical Research recommends that NIH receive at least $34.5 billion in FY 2017 as the next step toward a multi-year increase in our nation's investment in medical research.

DRAFT

Project Angel Heart
a meal with heart gives hope

Testimony Prepared by Erin Pulling, President and CEO of Project Angel Heart, for the United State House Subcommittee on Labor, Health and Human Services, Education, and Related Agencies addressed to the Department of Health and Human Services

April 15, 2015

We are pleased to submit this testimony to the Members of this Subcommittee on the urgency of continuing to support the Ryan White Program through the Appropriations process and increasing funding for the domestic HIV/AIDS portfolio in Fiscal Year 2017 (FY17). This support and funding will be decisive for achieving the goals of the National HIV/AIDS Strategy (NHAS) 2020, the AIDS Free Generation and halting the devastating effects of the HIV Treatment Cascade.

Project Angel Heart is part of a nationwide coalition, the Food is Medicine Coalition, of food and nutrition services providers, affiliates and their supporters across the country that provide food and nutrition services to people living with HIV/AIDS (PWH) and other chronic illnesses. In our service area, we provide 318,665 medically tailored, home delivered meals annually. Collectively, the Food is Medicine Coalition is committed to increasing awareness of the essential role that food and nutrition services (FNS) play in successfully treating HIV/AIDS and to expanding access to this indispensable intervention for people living with other severe illnesses.

1.) Why Food and Nutrition Services (FNS) Matter for PWH

While adequate food and nutrition are basic to maintaining health for all persons, good nutrition is crucial for the management of HIV infection. Proper nutrition is needed to increase absorption of medication, reduce side effects, and maintain healthy body weight. Research has identified the virus as an independent risk factor for cardiovascular, liver and kidney disease, cancer, osteoporosis and stroke. Several HIV medications can cause nausea and vomiting and some can affect lab results that test lipids and kidney and liver function. These compounding health effects, caused by the virus and its medications, reinforce the important role a nutrient-rich diet plays in a patient's overall care plan. In addition, providing food and nutrition services can serve to facilitate access and engagement with medical care, especially among vulnerable populations.

The Food and Nutrition Services category within the Ryan White Program includes medical nutritional therapy (MNT) and food and nutrition services (FNS). MNT covers nutritional diagnostic, therapy, and counseling services focused on prevention, delay or management of diseases and conditions, and involves an in-depth assessment, periodic reassessment and intervention provided by a licensed, Registered Dietitian Nutritionist (RDN) outside of a primary care visit. The range of FNS provided through the Ryan White program complements the needs of PWH at any stage of their illness. For those who are most mobile, there are congregate meals,

4.) FNS and the National HIV/AIDS Strategy (NHAS)

Access to FNS for PWH is fundamental to fulfilling the goals of the NHAS.

- **NHAS Goal: Reducing new HIV infections:** PWH who are food insecure are less likely to have undetectable viral loads in a statistically significant way. Undetectable viral loads prevent transmission 96% of the time[x], thus, FNS is key to prevention[xi].
- **NHAS Goal: Increasing access to care and improving health outcomes for people living with HIV:** PWH who receive effective FNS are more likely to keep scheduled primary care visits, score higher on health functioning, are at lower risk for inpatient hospital stays and are more likely to take their medicines[xii].
- **NHAS Goal: Reducing HIV-related disparities and health inequities:** By providing FNS to PWH who are in need largely because of poverty, we improve health outcomes, thereby reducing health disparities[xiii].
- **NHAS Goal: Achieving a more coordinated national response to the HIV epidemic:** There remains a tremendous variation by state in coverage of food and nutrition services both inside and outside of Ryan White, making support for Ryan White HIV Program all the more needed. Ultimately, if we are going to achieve a more coordinated national response to the HIV epidemic and our quest to reduce healthcare spending nationwide, FNS must be included in all healthcare reform efforts, including Ryan White and the ACA.

Conclusion

We are deeply aware of the difficult decisions that face the members of the Committee in the current fiscal environment. Yet, research shows that investment in FNS, with the great return in prevention and retention in HIV care, are vital to lowering the number of new infections in the domestic HIV epidemic and ultimately reducing healthcare costs and preserving healthcare resources for the future. A client's diet can literally have life and death consequences. When people are severely ill, good nutrition is one of the first things to deteriorate, making recovery and stabilization that much harder, if not impossible. Early and reliable access to medically-appropriate FNS helps PWH live healthy and productive lives, produces better overall health outcomes and reduces health care costs.

Along with our colleagues, we appreciate the opportunity to offer this testimony regarding the FY 2017 Appropriations process. We are also pleased to offer our assistance and expertise, including information from our Research Library.

Thank you.

Erin Pulling
President & CEO
Project Angel Heart
4950 Washington Street
Denver, CO 80216
303-830-0202
epulling@projectangelheart.org

4.) FNS and the National HIV/AIDS Strategy (NHAS)

Access to FNS for PWH is fundamental to fulfilling the goals of the NHAS.

- **NHAS Goal: Reducing new HIV infections:** PWH who are food insecure are less likely to have undetectable viral loads in a statistically significant way. Undetectable viral loads prevent transmission 96% of the time[x], thus, FNS is key to prevention[xi].
- **NHAS Goal: Increasing access to care and improving health outcomes for people living with HIV:** PWH who receive effective FNS are more likely to keep scheduled primary care visits, score higher on health functioning, are at lower risk for inpatient hospital stays and are more likely to take their medicines[xii].
- **NHAS Goal: Reducing HIV-related disparities and health inequities:** By providing FNS to PWH who are in need largely because of poverty, we improve health outcomes, thereby reducing health disparities[xiii].
- **NHAS Goal: Achieving a more coordinated national response to the HIV epidemic:** There remains a tremendous variation by state in coverage of food and nutrition services both inside and outside of Ryan White, making support for Ryan White HIV Program all the more needed. Ultimately, if we are going to achieve a more coordinated national response to the HIV epidemic and our quest to reduce healthcare spending nationwide, FNS must be included in all healthcare reform efforts, including Ryan White and the ACA.

Conclusion

We are deeply aware of the difficult decisions that face the members of the Committee in the current fiscal environment. Yet, research shows that investment in FNS, with the great return in prevention and retention in HIV care, are vital to lowering the number of new infections in the domestic HIV epidemic and ultimately reducing healthcare costs and preserving healthcare resources for the future. A client's diet can literally have life and death consequences. When people are severely ill, good nutrition is one of the first things to deteriorate, making recovery and stabilization that much harder, if not impossible. Early and reliable access to medically-appropriate FNS helps PWH live healthy and productive lives, produces better overall health outcomes and reduces health care costs.

Along with our colleagues, we appreciate the opportunity to offer this testimony regarding the FY 2017 Appropriations process. We are also pleased to offer our assistance and expertise, including information from our Research Library.

Thank you.

Erin Pulling
President & CEO
Project Angel Heart
4950 Washington Street
Denver, CO 80216
303-830-0202
epulling@projectangelheart.org

[i] Aidala A, Yomogida M, Vardy Y & the Food & Nutrition Study Team. Food and Nutrition Services, HIV Medical Care, and Health Outcomes. New York State Department of Health: Resources for Ending the Epidemic, 2014. Available at https://www.health.ny.gov/diseases/aids/ending_the_epidemic/docs/key_resources/housing_and_supportive_services/chain_factsheet3.pdf

[ii] Academy of Nutrition and Dietetics (formerly American Dietetic Association). HIV/AIDS Nutrition Evidence Analysis Project at http://www.adaevidencelibrary.com/conclusion.cfm?conclusion_statement_id=250707 Accessed 29 July 2012.

[iii] Aidala A., Yomogida M., and the HIV Food & Nutrition Study Team (2011);
Singe AW,Weiser SD, McCoy, SI. Does Food Insecurity Undermine Adherence to Antiretroviral Therapy? A Systematic Review. AIDS Behav (2015) 19:1510–1526.

[iv] Ibid.

[v] Anema A, Chan K, Yip B, Weiser S, Montaner JSG, Hogg RS. Impact of food insecurity on survival among HIV-positive injection drug users receiving antiretroviral therapy in a Canadian cohort. 141st APHA Annual Meeting, Nov. 2-6, 2013. Boston, MA. Abstract #: 290277

[vi] Aidala A., Yomogida M., and the HIV Food & Nutrition Study Team (2011).

[vii] Gurvey J, Rand K, Daugherty S, Dinger C, Schmeling J, Laverty N. Examining Health Care Costs Among MANNA Clients and a Comparison Group. J Prim Care Community Health. (2013) 4:311-317

[viii] Ibid.

[ix] Rabeneck L, Palmer A, Knowles JB, Seidehamel RJ, Harris CL, Merkel KL, Risser JMH, Akrabawi SS. A randomized controlled trial evaluating nutrition counseling with or without oral supplementation in malnourished HIV-infected patients. J Am Diet Assoc. (1998) 98: 434-438;Schwenk A, Steuck H, Kremer G. Oral supplements as adjunctive treatment to nutritional counseling in malnourished HIV-infected patients: randomized controlled trial. Clinical Nutrition (1999) 18(6): 371-374.

[x] M. S. Cohen *et al.*, Prevention of HIV-1 Infection with Early Antiretroviral Therapy. N. Engl. J. Med.(2011) 365, 493-505 . HPTN 052

[xi] Palar K, Laraia B, Tsai A, Weiser SD Food insecurity is associated with sexually transmitted infections and HIV serostatus among low income adults in the National Health and Nutrition Examination Survey (NHANES) (1999-2010). Presented at the American Public Health Association 141st Annual Meeting, Boston, MA, November 5, 2013.

[xii] Aidala A, Yomogida M, Vardy Y & the Food & Nutrition Study Team. Food and Nutrition Services, HIV Medical Care, and Health Outcomes. New York State Department of Health: Resources for Ending the Epidemic, 2014. Available at

xiii Weiser SD, Frongillo EA, Ragland K, Hogg RS, Riley ED, Bangsberg DR. Food insecurity is associated with incomplete HIV RNA suppression among homeless and marginally housed HIV-infected individuals in San Francisco. J Gen Intern Med. (2009) 24(1):14-20.

Project Angel Heart
a meal with heart gives hope

Testimony Prepared by Erin Pulling, President and CEO of Project Angel Heart, for the United State House Subcommittee on Labor, Health and Human Services, Education, and Related Agencies addressed to the Department of Health and Human Services

April 15, 2015

We are pleased to submit this testimony to the Members of this Subcommittee on the urgency of continuing to support the Ryan White Program through the Appropriations process and increasing funding for the domestic HIV/AIDS portfolio in Fiscal Year 2017 (FY17). This support and funding will be decisive for achieving the goals of the National HIV/AIDS Strategy (NHAS) 2020, the AIDS Free Generation and halting the devastating effects of the HIV Treatment Cascade.

Project Angel Heart is part of a nationwide coalition, the Food is Medicine Coalition, of food and nutrition services providers, affiliates and their supporters across the country that provide food and nutrition services to people living with HIV/AIDS (PWH) and other chronic illnesses. In our service area, we provide 318,665 medically tailored, home delivered meals annually. Collectively, the Food is Medicine Coalition is committed to increasing awareness of the essential role that food and nutrition services (FNS) play in successfully treating HIV/AIDS and to expanding access to this indispensable intervention for people living with other severe illnesses.

1.) Why Food and Nutrition Services (FNS) Matter for PWH

While adequate food and nutrition are basic to maintaining health for all persons, good nutrition is crucial for the management of HIV infection. Proper nutrition is needed to increase absorption of medication, reduce side effects, and maintain healthy body weight. Research has identified the virus as an independent risk factor for cardiovascular, liver and kidney disease, cancer, osteoporosis and stroke. Several HIV medications can cause nausea and vomiting and some can affect lab results that test lipids and kidney and liver function. These compounding health effects, caused by the virus and its medications, reinforce the important role a nutrient-rich diet plays in a patient's overall care plan. In addition, providing food and nutrition services can serve to facilitate access and engagement with medical care, especially among vulnerable populations.

The Food and Nutrition Services category within the Ryan White Program includes medical nutritional therapy (MNT) and food and nutrition services (FNS). MNT covers nutritional diagnostic, therapy, and counseling services focused on prevention, delay or management of diseases and conditions, and involves an in-depth assessment, periodic reassessment and intervention provided by a licensed, Registered Dietitian Nutritionist (RDN) outside of a primary care visit. The range of FNS provided through the Ryan White program complements the needs of PWH at any stage of their illness. For those who are most mobile, there are congregate meals,

walk-in food pantries and voucher programs. For those whose disease has progressed, home-delivered meals and home-delivered grocery bags complement their medical treatment.

Since 2006, HRSA has included MNT and FNS, provided under the guidance of RDNs, as a clinically effective **core medical service** in the Ryan White Program. These services play a critical role in ensuring that PWH enter and continue in primary medical care, adhere to their medications, and ultimately achieve viral suppression.

2.) FNS as a Care Completion Service Unique to Ryan White

Social and economic interventions, most often in the form of care completion service like food and nutrition services, are fundamental to making health care work for PWH. Support services for PWH are not covered in any comprehensive way by Medicaid or other public insurance initiatives that have been expanded by the Affordable Care Act. As the HIV epidemic in the United States increasingly impacts low-income individuals, support services help stabilize individuals living with or at risk of HIV. When needs are met, and life's emergencies are held at bay, PWH are poised to remain connected to care and treatment.

3.) Access to FNS and the Triple Aim

Access to appropriate food and nutrition services (FNS) are increasingly recognized as key to accomplishing the triple aim of national healthcare reform for PWH.

Better Health Outcomes

When clients get effective FNS and become food secure, they then keep scheduled primary care visits, score higher on health functioning, are at lower risk for inpatient hospital stays and are more likely to take their medicines[i]. Studies show both the health benefits of access to MNT and/or nutrition counseling for people with HIV infections[ii] and the resulting decreases in their healthcare costs. Compare these outcomes to PWH who are food insecure, who have:

- Lower CD4 counts & lower likelihoods of having undetectable viral loads[iii]
- More ER visits[iv] & increased morbidity and mortality[v]
- More missed primary care appointments & reduced use of antiretroviral therapy[vi].

Lower Healthcare Costs

Millions of dollars in healthcare expenditures are saved through the provision of FNS to PWH. A recent study comparing participants in a medically-tailored FNS program vs. a control group within a local managed care organization found that average monthly healthcare costs for PWH fell 80% in first three months after receiving FNS[vii]. If hospitalized, nourished clients' costs were 30% lower, their hospital length of stay was cut by 37% and they were 20% more likely to be able to be discharged to their homes rather than a more expensive institution[viii]. Furthermore, FNS are a very inexpensive intervention. For each day in a hospital saved, you can feed a person a medically-tailored diet for half a year.

Improved Patient Satisfaction

Studies show nutrition counseling improves quality of life[ix]. Members overwhelmingly report that our services help them live more independently, eat more nutritiously and manage their medical treatment more effectively.

4.) FNS and the National HIV/AIDS Strategy (NHAS)

Access to FNS for PWH is fundamental to fulfilling the goals of the NHAS.

- **NHAS Goal: Reducing new HIV infections:** PWH who are food insecure are less likely to have undetectable viral loads in a statistically significant way. Undetectable viral loads prevent transmission 96% of the time[x], thus, FNS is key to prevention[xi].
- **NHAS Goal: Increasing access to care and improving health outcomes for people living with HIV:** PWH who receive effective FNS are more likely to keep scheduled primary care visits, score higher on health functioning, are at lower risk for inpatient hospital stays and are more likely to take their medicines[xii].
- **NHAS Goal: Reducing HIV-related disparities and health inequities:** By providing FNS to PWH who are in need largely because of poverty, we improve health outcomes, thereby reducing health disparities[xiii].
- **NHAS Goal: Achieving a more coordinated national response to the HIV epidemic:** There remains a tremendous variation by state in coverage of food and nutrition services both inside and outside of Ryan White, making support for Ryan White HIV Program all the more needed. Ultimately, if we are going to achieve a more coordinated national response to the HIV epidemic and our quest to reduce healthcare spending nationwide, FNS must be included in all healthcare reform efforts, including Ryan White and the ACA.

Conclusion

We are deeply aware of the difficult decisions that face the members of the Committee in the current fiscal environment. Yet, research shows that investment in FNS, with the great return in prevention and retention in HIV care, are vital to lowering the number of new infections in the domestic HIV epidemic and ultimately reducing healthcare costs and preserving healthcare resources for the future. A client's diet can literally have life and death consequences. When people are severely ill, good nutrition is one of the first things to deteriorate, making recovery and stabilization that much harder, if not impossible. Early and reliable access to medically-appropriate FNS helps PWH live healthy and productive lives, produces better overall health outcomes and reduces health care costs.

Along with our colleagues, we appreciate the opportunity to offer this testimony regarding the FY 2017 Appropriations process. We are also pleased to offer our assistance and expertise, including information from our Research Library.

Thank you.

Erin Pulling
President & CEO
Project Angel Heart
4950 Washington Street
Denver, CO 80216
303-830-0202
epulling@projectangelheart.org

[i] Aidala A, Yomogida M, Vardy Y & the Food & Nutrition Study Team. Food and Nutrition Services, HIV Medical Care, and Health Outcomes. New York State Department of Health: Resources for Ending the Epidemic, 2014. Available at https://www.health.ny.gov/diseases/aids/ending_the_epidemic/docs/key_resources/housing_and_supportive_services/chain_factsheet3.pdf

[ii] Academy of Nutrition and Dietetics (formerly American Dietetic Association). HIV/AIDS Nutrition Evidence Analysis Project at http://www.adaevidencelibrary.com/conclusion.cfm?conclusion_statement_id=250707 Accessed 29 July 2012.

[iii] Aidala A., Yomogida M., and the HIV Food & Nutrition Study Team (2011);
Singe AW,Weiser SD, McCoy, SI. Does Food Insecurity Undermine Adherence to Antiretroviral Therapy? A Systematic Review. AIDS Behav (2015) 19:1510–1526.

[iv] Ibid.

[v] Anema A, Chan K, Yip B, Weiser S, Montaner JSG, Hogg RS. Impact of food insecurity on survival among HIV-positive injection drug users receiving antiretroviral therapy in a Canadian cohort. 141st APHA Annual Meeting, Nov. 2-6, 2013. Boston, MA. Abstract #: 290277

[vi] Aidala A., Yomogida M., and the HIV Food & Nutrition Study Team (2011).

[vii] Gurvey J, Rand K, Daugherty S, Dinger C, Schmeling J, Laverty N. Examining Health Care Costs Among MANNA Clients and a Comparison Group. J Prim Care Community Health. (2013) 4:311-317

[viii] Ibid.

[ix] Rabeneck L, Palmer A, Knowles JB, Seidehamel RJ, Harris CL, Merkel KL, Risser JMH, Akrabawi SS. A randomized controlled trial evaluating nutrition counseling with or without oral supplementation in malnourished HIV-infected patients. J Am Diet Assoc. (1998) 98: 434-438;Schwenk A, Steuck H, Kremer G. Oral supplements as adjunctive treatment to nutritional counseling in malnourished HIV-infected patients: randomized controlled trial. Clinical Nutrition (1999) 18(6): 371-374.

[x] M. S. Cohen *et al.*, Prevention of HIV-1 Infection with Early Antiretroviral Therapy. N. Engl. J. Med.(2011) 365, 493-505 . HPTN 052

[xi] Palar K, Laraia B, Tsai A, Weiser SD Food insecurity is associated with sexually transmitted infections and HIV serostatus among low income adults in the National Health and Nutrition Examination Survey (NHANES) (1999-2010). Presented at the American Public Health Association 141st Annual Meeting, Boston, MA, November 5, 2013.

[xii] Aidala A, Yomogida M, Vardy Y & the Food & Nutrition Study Team. Food and Nutrition Services, HIV Medical Care, and Health Outcomes. New York State Department of Health: Resources for Ending the Epidemic, 2014. Available at

xiii Weiser SD, Frongillo EA, Ragland K, Hogg RS, Riley ED, Bangsberg DR. Food insecurity is associated with incomplete HIV RNA suppression among homeless and marginally housed HIV-infected individuals in San Francisco. J Gen Intern Med. (2009) 24(1):14-20.

Testimony of William J Whited
Oklahoma State Long-Term Care Ombudsman
Member, National Association of State Long-Term Care Ombudsman Programs
2401 NW 23rd Street, Suite 40
Oklahoma City, OK 73107
1 (405) 521 – 6734
William.Whited@OKDHS.org

Prepared for the House Appropriations Subcommittee on Labor, Health and Human Services, Education, and Related Agencies – Addressing the Administration for Community Living (ACL)

I am pleased to present this testimony on behalf of residents and tenants residing in Oklahoma long-term care facilities in collaboration with the National Association of State Long-Term Care Ombudsman Programs (NASOP). Thank you for your past support of the Long-Term Care Ombudsman Program (LTCOP) and all the vulnerable citizens that it serves. This statement and the following funding recommendations are submitted for the Fiscal Year 2017 for the Long-Term Care Ombudsman Programs administered through the Administration for Community Living (ACL).

Thank you for your support of the recently passed reauthorization of the Older American Act. The bill is awaiting the President's signature. This legislation, which had strong bipartisan support, does several important things to strengthen and improve the Long-Term Care Ombudsman Program, including:

- Mandating the program to serve all residents of long-term care facilities, including those individuals with disabilities, which expands our services to residents under the age of 60;
- Enabling the program to advocate for residents who cannot provide informed consent and have no resident representative – the Ombudsman can now advocate for the best interests of the resident; and
- Improving our ability to advocate for residents who are victims of guardianship abuse.

In addition, Congress' reauthorization of the Older Americans Act continues to encourage regular, non-compliant facility visits, which are a cost effective vehicle to identify and resolve problems, avoiding the more costly regulatory system.

In addition, new federal regulations for the Long-Term Care Ombudsman Program reinforce the reauthorized Older Americans Act. All of these tools will increase our ability to serve residents in the growing number of assisted living facilities caring for the baby boomer generation. In order to adequately serve the growing number of long-term care facility residents, NASOP asks for the following:

First, we request $5 million to **support the work of the LTCOP under the Elder Justice Act.** This appropriation would allow states to hire additional staff and leverage that staff to recruit additional volunteers to help support the investigation of complaints of abuse, neglect, and

exploitation of residents of nursing home and assisted living facilities. To date, no EJC funds have been provided for the LTCOP.

Second, we request $20 million to **support 333 additional Ombudsman** (salaried staff) at an estimated $60,000 average annual salary/fringe benefits and necessary staff training. The requests adds new ombudsman positions specifically dedicated to providing Ombudsman services to residents of assisted living facilities and other community-based long-term care delivery systems, which currently suffer from a significant lack of personnel resources around the country.

Third, we request $16.83 million authorized under Title VII of the Older Americans Act for LTCOPs **to restore funding back to the FY 2011 level**. Programs in every district and state are suffering from recent cuts. These funds would help in a partial way to restore our reduced ability to visit residents in nursing homes.

The primary function of the LTCOP in the federal OAA is to identify, investigate, and resolve complaints that relate to action, inaction or decisions that may adversely affect the health, safety, welfare, and rights of residents of long-term care facilities. Ombudsman representatives work with the consent and at the direction of residents in the resolution of their problems. They visit residents living in nursing homes and residential care homes. Ombudsman representatives ask them about problems or concerns they have and if they need or want our help to resolve these issues. Ombudsman representatives act as their advocates. We strongly believe that our work not only improves the quality of life for millions of long-term care facility residents, but also saves Medicare and Medicaid resources by avoiding unnecessary costs associated with poor quality care.

Nationally, in Fiscal Year 2014, nearly 8,200 volunteers, including individuals certified to investigate complaints, and 986 staff (full-time equivalent) served in the LTCOP. Ombudsman representatives investigated and worked to resolve 188,599 complaints made by 125,642 individuals. Ombudsmen were able to resolve or partially resolve 76%, or more than three out of every four complaints investigated. In addition, Ombudsman representatives provided information or consultation on rights, care and related services approximately 490,000 times.

In Federal Fiscal Year 2015 Oklahoma had 596 long-term care facilities with 43,937 licensed beds. With an estimated occupancy rate of 68% the Oklahoma LTCOP is responsible for advocating for 29,877 Oklahoman's residing in long-term care facilities. The Oklahoma Office of State Long-Term Care Ombudsman consists of the State Long-Term Care Ombudsman, Deputy State Long-Term Care Ombudsman, an Administrative Programs Officer, One Administrative Assistant, two Program Field Representatives, twenty-three fulltime Ombudsman Supervisors, one halftime Ombudsman Supervisor and numerous volunteers.

In federal Fiscal Year 2014, Oklahoma's LTCOP received 5,646 complaints by or on behalf of residents; and provided 9,216 consultations, education sessions, visits, and other advocacy activities. In Federal Fiscal Year 2015 Oklahoma's LTCOP received 5,680 complaints by or on behalf of residents; and provided 9,464 consultations, education sessions, visits and other advocacy activities. The program completed the services with a limited workforce that is under

ever increasing caseloads and mounting fiscal constraints. The State of Oklahoma has declared two budget failures alrcady in State Fiscal Year 2016 that have resulted in 7% budget reductions to state agencies. Oklahoma also estimates a 1.3 billion dollar budget shortfall for State Fiscal Year 2017. We are grateful for the funding that wc do have, but feel that the federal funding for the operation of the Oklahoma LTCOP should be increased. Currently federal Older Americans Act funding comprises less than half of the funding required to maintain the Oklahoma program at its current level and with the declines in statc revenue it is unlikely that state dollars will be available to maintain the program. The additional funding would not only support elder justice activities it would support avenues to recruit more volunteers and ultimately improve the quality of care and quality of life of Oklahoma's long-term care facility residents.

We understand that this Subcommittee faces a strained financial situation, but a continued commitment to Ombudsman programs advocating for the health care needs and safety of millions of older adults living in nursing homes and assisted living facilities across the nation should remain a high priority. Since 1978, the LTCOP has been a core program of the OAA. It is the only program in the OAA that specifically serves residents of nursing homes and assisted living facilities. We all appreciate and value the importance of living in one's own home. The OAA provides critically needed home and community based services that often delay institutionalization. However, some elders can no longer live safely in their own homes and must move at some point in their lives to either an assisted living facility or a nursing home. These residents are usually frail and extremely vulnerable and rely on the advocacy services of the LTCOP.

Demand for our services and advocacy 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. These violations put facility residents in immediate jeopardy of harm. This trend suggests a frightening decline in the quality of long-term care services. Ombudsmen are needed now more than ever in nursing homes, board and care facilities, and in assisted living communities. As well, the demand placed on the program by the need to assist residents who are relocating from long-term care facilities that are downsizing or closing their doors continues to complicate ombudsman programs' daily operations.

Administrators in many long-term care facilities have recognized the value and benefit of having ombudsmen assist with staff training and consultation and this form of outreach has also placed an increasing strain on available advocacy resources. In order to improve advocacy and services available to residents of long-term care facilities, the Oklahoma Office of the State Long-Term Care Ombudsman and NASOP supports the aforementioned funding levels.

Overall, Ombudsmen offer valuable consumer protections to residents and provide a voice for those unable to speak for themselves. Every day in America, 10,000 more persons reach the age of 65 years. With a rapidly growing older population, LTCOPs can continue to enhance the quality of life, improve the level of care, protect the individual's rights and promote the dignity of Americans across the nation. NASOP, formed in 1985 as a non-profit organization, is

composed of state long-term care ombudsmen representing their state programs created by the Older Americans Act (OAA).

Thank you for your ongoing support.

STATEMENT OF THE AMERICAN INDIAN HIGHER EDUCATION CONSORTIUM
SUBMITTED TO THE U.S. HOUSE OF REPRESENTATIVES - COMMITTEE ON APPROPRIATIONS
SUBCOMMITTEE ON LABOR, HHS, EDUCATION, AND RELATED AGENCIES
April 15, 2016

This statement includes the Fiscal Year 2017 (FY 2017) requests of the nation's Tribal Colleges and Universities (TCUs). The following is a summary of our requests including Department, program, and amount requested:

Department of Education
Office of Postsecondary Education
- HEA Title III-A, Sec. 316: $60,000,000 (discretionary and mandatory)
- Perkins Career and Technical Education Programs (Sec. 117): $10,000,000

Office of Career, Technical, and Adult Education
- American Indian Adult and Basic Education: $8,000,000, from existing funds

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

U.S. Department of Education

I. Higher Education Act Programs

Strengthening Developing Institutions, Title III-A Sec. 316: ***TCUs urge the Subcommittee to restore the discretionary and mandatory funding for HEA Title III-A, Sec. 316 to $60,000,000 in FY 2017.***
Titles III and V of the Higher Education Act support institutions that enroll large proportions of financially disadvantaged students. The TCUs, which are *truly* developing institutions, are funded under Title III-A Sec. 316 and provide quality higher education opportunities to some of the most rural, impoverished, and historically underserved people in the country. In fact, more than 50 percent of our students are first generation. Average family income is $15,260; local unemployment rates often exceed 50 percent. The goal of HEA-Titles III/V programs is "to improve the academic quality, institutional management and fiscal stability of eligible institutions... to increase their self-sufficiency and strengthen their capacity to make a substantial contribution to the higher education resources of the Nation." The TCU Title III-A program is specifically designed to address the critical, unmet needs of American Indian students and their communities, to effectively prepare them to succeed in a globally competitive workforce. Yet, in FY 2011 this program was cut by over 11 percent and received subsequent cuts, including sequestration, until last year. Despite a small increase in FY 2016, TCUs still have not recovered from the earlier cuts to this vitally important program. In FY 2016, the TCU section (Sec.316) was the *only* Title III/V program that emerged from Conference with a funding level *BELOW* the level passed by either the House or Senate in their respective appropriations bills.

TRIO: Retention and support services are vital to achieving the national goal of having the highest proportion of college graduates in the world by 2020. TRIO programs were created out of a recognition that college access is not enough to ensure advancement and that multiple factors work to prevent successful completion by many low-income and first-generation students and students with disabilities. In addition to providing the maximum Pell Grant award level, it is critical that Congress sustain and increase support for TRIO programs so that low-income and minority students have the support they need to access and complete postsecondary education programs.

Pell Grants: The importance of Pell Grants to TCU students cannot be overstated. Eighty-five percent of TCU students receive Pell Grants, primarily because student income levels are so low and they have far less access to other sources of financial aid than students at state-funded and other mainstream institutions. At TCUs, Pell Grants are doing exactly what they were intended to do: they are serving the needs of the lowest income students by helping them gain access to quality postsecondary education, an essential step toward becoming active, productive members of the workforce.

II. **Carl D. Perkins Career and Technical Education Programs**

Tribally Controlled Postsecondary Career and Technical Institutions: ***AIHEC requests $10,000,000 to fund grants under Sec. 117 of the Perkins Act.*** Section 117 of the Carl D. Perkins Career and Technical Education Act provides a competitively awarded grant opportunity for tribally chartered and controlled career and technical institutions, which are providing vitally needed workforce development and job creation education and training programs to American Indians and Alaska Natives (AI/ANs) from tribes and communities with some of the highest unemployment rates in the nation. Jayvion Chee of Rabbitbrush, NM is an example of a young Native student benefiting from this modest program. In March, Jayvion was named as Navajo Technical University's (NTU) Student of the Year. Jayvion spent much of last year working on a geographic information technology (GIT) degree project that assessed the potential impacts on water resources posed by hydraulic fracturing in San Juan County, NM. Jayvion used his education in NTU's Associate of Applied Science-GIT degree program to map current natural gas fracking wells to better understand the potential risks associated with the fracking process. Through his research, he found that 87 documented wells within the San Juan region could possibly lead to adverse impacts on local communities - including the land of which his grandfather resides. He has now presented the results of his research at national STEM and education conferences around the country.

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

III. **Adult Education and Family Literacy Act – Adult Education, Basic Grants to States**

American Indian Adult and Basic Education: ***AIHEC requests the Subcommittee to direct that $8,000,000 of the approximately $582,000,000 appropriated for Adult Education & Literacy State Formula Grants be made available to make competitive awards to TCUs to help meet the growing demand for adult basic education and GED training services in tribal communities.*** This program, which Congress stopped funding in the mid-1990s, was designed to support much-needed adult basic education (ABE) and GED training for AI/ANs through federally recognized Indian Tribes and TCUs. (A specific Tribal/TCU set-aside within any federal-to-state block grant program is necessary, because states generally do not provide funding to Indian tribes or TCUs for programs on federal trust land, even when there is no comparable federal program for tribes.) In the absence of dedicated funding for American Indians and a severe constraint on – and in many cases, a complete lack of – funding allocated from state programs to TCUs, our colleges must find a way, often using already insufficient institutional operating funds, to provide ABE and GED classes for AI/ANs that the present K-12 Indian education system has failed. TCUs, like most community colleges, are open door institutions. More than 71 percent of all TCU students need developmental education in at least one subject (math, science, or reading/composition) before beginning college-level coursework and 15 percent of all first-time entering TCU students must first

prepare for and pass a high school equivalency test, yet little or no funding is available for these critical programs. Challenges have intensified since the GED test was revamped in January 2014. The new computer-based and more rigorous test has posed difficulties for many TCUs to implement (with little or no funding for staff professional development or technical assistance) and much more difficult for American Indians to pass. One TCU, Oglala Lakota College, reports that prior to the new GED test, an average of 29 students successfully passed the GED test each year and enrolled in the college. Often, these students became some of the OLC's most successful graduates. However, since the new GED was implemented, only seven students passed in 2014 and two in 2015. OLC and all of the TCUs are in critical need of adequate and stable funding to provide rural AI/ANs the preparation and testing they need to move from victims of generational poverty and unemployment to productive and tax-paying members the U.S. workforce.

U.S. DEPARTMENT OF HEALTH and HUMAN SERVICES PROGRAMS

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

Tribal Colleges and Universities Head Start Partnership Program: ***AIHEC requests that $8 million of the $9.6 billion proposed for making payments under the Head Start Act be designated for the TCU-Head Start Partnership program, as reauthorized in PL 110-134, so that TCUs can provide high-quality, culturally appropriate training for teachers and workers in Indian Head Start programs.*** With the reauthorization of the Head Start program in the mid-1990s, Congress mandated that by 2013, 50 percent of Head Start teachers nationwide must have at least a baccalaureate degree in Early Childhood Education and *all* teacher assistants must have a child development associate credential or be enrolled in an associate's degree program. Today, 73 percent of Head Start teachers nationwide hold the required bachelor's degree; but only 39 percent of Head Start teachers in Indian Country (Region 11) meet the requirement, and only 38 percent of workers met the associate-level requirements. This disparity in preparation and teaching demands our attention: AI/AN children deserve – and desperately need -- qualified teachers. TCUs are ideal catalysts for filling this inexcusable gap. From 2000 to 2007, the U.S. Department of Health and Human Services provided modest funding for the TCU-Head Start Program, which helped TCUs build capacity in early childhood education by providing scholarships and stipends for Indian Head Start teachers and teacher's aides to enroll in TCU early childhood programs. Before the program ended in 2007 (ironically, the same year that Congress specifically authorized the program in the Head Start Act), TCUs had trained more than 400 Head Start workers and teachers, many of whom have since left for higher paying jobs in elementary schools. Today, Tribal Colleges such as Salish Kootenai College in Pablo, Montana are providing culturally based early childhood education free of charge to local Head Start workers. With restoration of this modestly funded program, similar programs could be available to the teachers and aides throughout Indian Country.

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

New TCU Opioid/Substance Abuse Research and Prevention Program: ***AIHEC requests that as part of the ongoing national opioid/prescription drug initiative, $10 million be appropriated to establish a Tribal Colleges and Universities Substance Abuse/Behavioral Health Research and Prevention Initiative within SAMHSA to strategically identify and address the drug abuse and behavioral health issues impacting Native youth.*** The most at-risk population in the United States is American Indian and Alaska Native college-aged youth (ages 15-24). Suicide of friends, classmates, and relatives; alcohol and substance abuse; domestic violence and abuse; bullying and extreme poverty are all too common to Tribal

College students. In fact, a seminal behavior health survey of TCU students[1], revealed that 50.4 percent of TCU students surveyed reported being physically intimidated, assaulted, or bullied/excessively teased by a peer. Twenty-four percent – one-quarter – reported having used opioids, compared to less than 9 percent of mainstream college students (in a 2013 national survey, which is the only comparable data available). Of the TCU students who had used opioids, 25 percent reported feeling signs of addiction, and nearly 34 percent had taken opioids without a prescription in the last three months. AIHEC and partnering entities are on the leading edge nationally in collecting data of this type due in large part to modest grants from the under-funded "Native American Research Centers on Health" program operated by the National Institutes of Health and the Indian Health Service (and in needed of increased funding). Data of this type has never been collected nationally among college students, but the TCUs know that we must get a handle on this problem before it spirals out of control. Without serious, sustained, and community-based intervention, it will rapidly spiral out of control. Already, the death rates among American Indians from heroin overdose has increased 236 percent between 2010 and 2014. The Centers for Disease Control and Prevention (CDC) reported that in 2014, American Indians were dying at *double or triple* the rates of African-Americans and Latinos from opioid, including heroin, addiction.

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

As engaged, place-based institutions, Tribal Colleges are committed to addressing the many challenges facing our communities, including the growing opioid epidemic. TCUs are leading the way through student-based participatory research to identify the specific needs of tribal communities (youth and students), so that community-relevant solutions can be identified and culturally adapted, tested, and then shared with others. SAMHSA, which has modest tribal drug abuse prevention programs and an ongoing effort with Historically Black Colleges and Universities, seems an appropriate agency to administer a TCU Behavioral Health Research and Prevention Initiative to assist TCUs, working with local communities and researchers, in taking strategic steps to identify the behavioral health challenges, develop or adapt innovative and community-practiced intervention strategies, forge relationships with local and regional non-profit providers, and create and test models that can be replicated and adapted at other TCUs and tribal communities. This targeted approach will help ensure that tribal youth have the same chance as others to become healthy, productive adults who will greatly benefit their local communities and the nation as a whole.

We respectfully request that the Members of the Subcommittee recognize the significant contribution of the Tribal Colleges and Universities to our students, their communities, and the nation as a whole by continuing and expanding the federal investment our institutions and careful consideration our FY 2017 appropriations needs and requests.

---

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

THE PEW CHARITABLE TRUSTS

2005 Market Street, Suite 2800 215.575.9050 Phone
Philadelphia, PA 19103-7077

901 E Street NW 202.552.2000 Phone
Washington, DC 20004
www.pewtrusts.org

April 15, 2016

The Honorable Roy Blunt
Chairman
Subcommittee on Labor, Health and Human Services, Education, and Related Agencies
Committee on Appropriations
United States Senate
Washington, DC 20510

The Honorable Tom Cole
Chairman
Subcommittee on Labor, Health and Human Services, Education, and Related Agencies
Committee on Appropriations
United States House of Representatives
Washington, DC 20515

The Honorable Patty Murray
Ranking Member
Subcommittee on Labor, Health and Human Services, Education, and Related Agencies
Committee on Appropriations
United States Senate
Washington, DC 20510

The Honorable Rosa DeLauro
Ranking Member
Subcommittee on Labor, Health and Human Services, Education, and Related Agencies
Committee on Appropriations
United States House of Representatives
Washington, DC 20515

Dear Chairmen Blunt and Cole, and Ranking Members Murray and DeLauro:

The Pew Charitable Trusts is an independent nonpartisan, nonprofit research and policy organization. Our work to address substance use disorders focuses on developing and supporting policies that 1) reduce the inappropriate use of prescription drugs while ensuring that patients have access to effective pain management, and 2) expand access to effective treatment for substance use disorders through increased use of medication-assisted treatment (MAT). Pew urges you to include funding in the fiscal year (FY) 2017 Labor, Health and Human Services, Education, and Related Agencies Appropriations bill to support efforts to combat the opioid epidemic.

Drug overdose rates hit record levels in 2014, the most recent year for which data are available. This increase was driven by opioids, such as heroin and prescription pain relievers, which were involved in more than 28,000 overdose deaths.[i] According to Dr. Tom Frieden, director of the Centers for Disease Control and Prevention (CDC), "The increasing number of deaths from opioid overdose is alarming. The opioid epidemic is devastating American families and communities. To curb these trends and save lives, we must help prevent addiction and provide support and treatment to those who suffer from opioid use disorders."

Decades of research have unequivocally demonstrated that the most effective treatment for substance use disorder is MAT, which pairs medications approved by the Food and Drug Administration with behavioral therapy. Despite the evidence, MAT has been adopted in less than half of private-sector treatment programs and even in programs that do offer MAT, just over one-third of patients receive it.[ii] The President's FY 2017 Budget request includes funding for a

number of initiatives that would substantially expand access to MAT for opioid use disorder and, ultimately, save lives.

The President's FY 2017 Budget requests $50.1 million that would enable the Substance Abuse and Mental Health Services Administration (SAMHSA) to support 23 new state grants to expand access to MAT, recovery support services, and coordinate human immunodeficiency virus/hepatitis C treatment. The grants, targeted to states that have high rates of treatment admissions for opioid use disorders, would increase access to effective, comprehensive, coordinated care for these patients. This program currently funds grants in 11 states, but the demand for services has continued to rise in parallel with increased opioid misuse and many more states could benefit from this support.

The President's proposal also includes $10 million for a new SAMHSA demonstration program on expanding buprenorphine prescribing authority. Federal law currently limits the prescribing of buprenorphine to physicians. This restriction exists despite the fact that there are no federal restrictions on nurse practitioners and physician assistants prescribing any other drug, including opioid pain relievers, which are the largest contributor to overdose deaths. This demonstration would test the safety and effectiveness of allowing nurse practitioners and physician assistants to prescribe buprenorphine for the treatment of substance use disorder. Research published last year in the American Journal of Public Health demonstrates that the current supply of physician prescribers of buprenorphine is not sufficient to treat the growing number of patients with opioid use disorder.[iii] This research would be a critical first step in understanding how nurse practitioners and physician assistants, who are often the only primary care providers in rural areas, could help more patients access MAT.

Another important item in the President's FY 2017 Budget is $10 million to support a Rural Opioid Overdose Reversal Program run by the Health Resources and Services Administration. These funds would be used to increase the availability of naloxone, a drug that blocks the effects of opioids and reverses overdose, in rural communities, and to refer patients with drug dependency to treatment centers. According to the CDC, naloxone was administered to reverse more than 26,000 overdoses between 1996 and 2014.[iv] However, this drug could be much more widely used in rural areas. A 2015 study found that rural communities are disproportionately affected by underutilization of naloxone, despite the fact that rural residents suffer a higher rate of opioid overdose than in other parts of the country.[v] This program would take steps to narrow that gap.

Pew strongly urges you to support the requests in the President's Budget that would make MAT more accessible and effective. Should you have any questions or if we can be of assistance with your work please contact Lindsey Berman at 202-540-6958 or lberman@pewtrusts.org. Pew thanks you for your leadership.

Sincerely,

Cynthia Reilly

Cynthia Reilly, B.S. Pharm.
The Pew Charitable Trusts

[i] Centers for Disease Control and Prevention. Increases in Drug and Opioid Overdose Deaths — United States, 2000–2014. Morbidity and Mortality Weekly Report 2016; 62(50):1378-82.
[ii] Knudsen, H. K., Abraham, A. J., & Roman, P. M. (2011). Adoption and implementation of medications in addiction treatment programs. Journal of Addiction Medicine, 5(1), 21.
[iii] Jones, C. M., Campopiano, M., Baldwin, G., & McCance-Katz, E. (2015). National and state treatment need and capacity for opioid agonist medication-assisted treatment. American journal of public health, 105(8), e55-e63.
[iv] Centers for Disease Control and Prevention. Opioid Overdose Prevention Programs Providing Naloxone to Laypersons — United States, 2014. Morbidity and Mortality Weekly Report 2014; 64(23);631-635.
[v] Faul, M., Dailey, M. W., Sugerman, D. E., Sasser, S. M., Levy, B., & Paulozzi, L. J. (2015). Disparity in naloxone administration by emergency medical service providers and the burden of drug overdose in US rural communities. American journal of public health, 105(S3), e26-e32.

Testimony of the Friends of NIDDK Regarding Fiscal Year (FY) 2017 Appropriations for the National Institute of Diabetes and Digestive and Kidney Diseases

U.S. House Committee on Appropriations Subcommittee on Labor, Health and Human Services, Education, and Related Agencies

April 15, 2016

Submitted by Jim Twaddell, Staff Consultant, Friends of NIDDK

For the Fiscal Year (FY) 2017 funding cycle, the Friends of NIDDK encourages the Subcommittee to increase funding for research programs and activities at the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) that focus on preventing acute and chronic disease and other illnesses in adults as well as youth, and reducing health disparities. In particular, **the Friends of NIDDK request a funding level of $2.165 billion in FY 2017 for the Institute.** This funding level is an increase of approximately 10% over the FY 2016 omnibus bill. Given the large burden that acute and chronic diseases place on the U.S. health care system, economy, and quality of life years, the Friends of NIDDK believe that increased support for efforts in FY 2017 to will reduce this burden is warranted.

The Friends of NIDDK is a coalition of professional societies and patient advocacy groups with a vested interest in promoting and sustaining the vital research activities of the NIDDK. The Friends of NIDDK was established in 2013 with the vision of uniting organizations to speak with one voice about the important research being conducted by the Institute and to ensure that the investment in the NIDDK is deepened in future years. The Friends of NIDDK engage Members of Congress and other stakeholders on the prolific scientific advances made through the Institute's ongoing research and the critical importance of increased federal funding for future scientific initiatives. In just the short time since its inception, nearly 50 national and local organizations have joined the Friends of NIDDK to rally their support of the Institute's activities.

About NIDDK

NIDDK is the fifth largest institute at the National Institutes of Health and coordinates research on many of the most serious diseases affecting public health. The mission of NIDDK is to "conduct and support medical research and research training and to disseminate science-based information on diabetes and other endocrine and metabolic diseases; digestive diseases, nutritional disorders, and obesity; and kidney, urologic, and hematologic diseases, to improve people's health and quality of life."

The NIDDK supports a wide range of medical research through grants to universities and other medical research institutions across the country, and supports scientists who conduct basic, translational, and clinical research across a broad spectrum of research topics and serious chronic diseases and conditions. In addition, the NIDDK supports research training for students and scientists at various stages of their careers and a range of education and outreach programs, including the National Diabetes Education Program, the National Kidney Disease

Education Program and the Weight-control Information Network, to bring science-based information to patients and their families, health care professionals, and the public.

U.S. Disease Burden

The diseases that are included within the NIDDK research portfolio are some of the most common, yet costly, diseases impacting Americans and demand increased research funding in FY 2017. Chronic diseases are the nation's leading causes of morbidity and mortality and account for 75 cents of every dollar spent on health care in the U.S. For example, nearly 30 million Americans have diabetes and 86 million have prediabetes. Diagnosed and undiagnosed diabetes, prediabetes and gestational diabetes cost the nation $322 billion a year, an increase of 48% in just five years. About 26 million American adults have chronic kidney disease (CKD) and millions of others are at increased risk, although NIH investments in kidney research are less than 1% of Medicare costs for kidney care. It is estimated that 1.4 million Americans suffer from Crohn's disease and ulcerative colitis with approximately 30,000 new cases diagnosed each year, costing more than $2.2 billion in direct and indirect costs annually in the United States. Urologic diseases affect people of all ages, result in significant health care expenditures, and may lead to substantial disability and impaired quality of life. Patients with cystic fibrosis, an inherited disease that primarily affects the lungs and digestive system, continue to face much lower life expectancy compared to healthy adults, despite dramatic advances in treatment. These diseases represent only a portion of the NIDDK research portfolio, but nonetheless underscore the need for continued investment.

NIDDK Successes

The researchers at NIDDK are collaborating and using innovative technologies to discover cross-cutting solutions that will ultimately reduce health care costs and improve quality of life for millions of Americans. NIDDK releases an annual report to illustrate the Institute's scientific advances, and incorporates personal stories of individuals that participate in NIDDK-sponsored clinical research. Funding of $2.165 billion in FY 2017 would allow NIDDK to move forward on the following recent innovations outlined in the report:

- A proposed human kidney biopsy project that would incorporate the systematic collection, storage, and preservation of kidney tissue-combined with advances in genetics and precision medicine-in order to lead to new research discoveries, treatments, and cures for kidney disease patients.

- Findings that indicate cells or exosomes that are shed by the primary tumor in the bloodstream can potentially be used as biomarkers when screening for Pancreatic Disease.

- New research has found a link between gut sensory cells and nerves. This connection shows that the gut is able to directly communicate about ingested nutrients to the nervous system.

- Advancing progress toward the development of an artificial pancreas for people with Type 1 diabetes by using smartphone technology.

- Research areas for treatment of liver disease including experimental cell based approaches for liver cell regeneration.

Thank you for this opportunity to present our views to the Subcommittee. We urge your FY 2017 appropriations decisions reflect the need to address the broad spectrum of diseases in the Institute's portfolio. We look forward to working with you to prevent chronic illness, improve the quality of lives, and save billions of dollars in health care spending through an increased investment in the NIDDK. Should you have any questions or require additional resources regarding NIDDK activities, please contact the Friends of NIDDK's Washington representative, Jim Twaddell, at Jim.Twaddell@dbr.com or (202) 230-5130.

AMCHP
ASSOCIATION OF MATERNAL & CHILD HEALTH PROGRAMS

House Committee on Appropriations
Subcommittee on Labor, Health & Human Services, Education, and Related Agencies

Testimony for the Record in Support of Appropriations for the Title V Maternal and Child Health Services Block Grant (Department of Health and Human Service)

April 15, 2016

Submitted by Lori Tremmel Freeman
Chief Executive Officer, Association of Maternal & Child Health Programs (AMCHP)

Chairman Cole, Ranking Member DeLauro and distinguished Subcommittee Members - I am grateful for this opportunity to submit written testimony on behalf of the Association of Maternal & Child Health Programs (AMCHP), our members, and the millions of women, children and families that are served by the Title V Maternal and Child Health (MCH) Services Block Grant. I am asking the Subcommittee to support an increase of $12 million in funding for the Title V MCH Services Block Grant for a total of $650 million in fiscal year 2017.

At this time, two of the most critical emerging public health issues facing the United States today - the Zika virus and the opioid use epidemic - have explicit consequences for maternal and child health. The Title V program stands ready to play an important role in our nation's response by employing evidence-based services and strategies that further the program's statutory purpose to improve the health of all mothers and children.

As you may know, the Title V MCH Block Grant already works to 1) ensure access to quality maternal and child health services, 2) reduce infant mortality and preventable diseases and conditions, and 3) provide and promote family centered, community-based, coordinated care for children with special health care needs and facilitate the development of community-based systems of services for such children and their families.

Thank you for recognizing the value provided by the MCH Block Grant and providing small increases in funding over the past few years. I know you and your colleagues understand that the current level of funding does not allow us to address all the health needs of our nation's women, children, fathers and families. We are proud of the recent progress in lowering our nation's infant mortality rate, reducing teen pregnancy and decreasing the incidence of childhood injury. However, despite recent strides, close to 24,000 babies tragically die each year. Many others are born too soon and cost our society upwards of $26 billion per year. Gaps in both private and public insurance create barriers for families needing services. Many pregnant women still smoke. The obesity epidemic continues to plague our country and the list goes on and on. In the face of these challenges, public health programs have already borne more than their fair share of deficit reduction with years of cuts and a budget cap that could cut funding even further.

We strongly urge you to reward programs that work and are showing results by providing a $12 million increase in funding for the federal investment in the Title V MCH Services Block Grant.

States and jurisdictions use the Title V MCH Block Grant formula funds to design and implement a wide range of maternal and child health programs that respond to locally defined needs. For example, the "Every Week Counts" initiative in Oklahoma, funded in part by Title V, demonstrated a 96% decrease in early elective deliveries between 2011-2014. In Mississippi, the Title V program is a partner in the Healthy Teens for a Better Mississippi initiative, which recently reported a 15% decrease in the state teen birth rate between 2012-2015.

One of the primary focus areas for state Title V programs is supporting systems of services for children and youth with special health care needs (CYSHCN). These systems serve a diverse group of children ranging from children with chronic conditions such as asthma or diabetes, to children with autism, to those with more medically complex health issues such as spina bifida or other congenital disorders and include children with behavioral or emotional conditions. Overall, CYSHCN are defined as children birth to age 21 who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and require health and related services of a type or amount beyond that required by children generally. In a recent national survey, children with a chronic condition represented approximately 15 percent of the entire child population in the United States.

Care coordination is an essential component of delivering services to children and youth with special health care needs. State Title V programs improve care coordination by working collaboratively with parents, providers and payers. In Colorado, the Title V CYSHCN program spearheaded an effort to streamline coordination of care by working to reduce duplication of services and unnecessary costs in collaboration with Medicaid and other programs that serve these children.

Another key component of the Title V MCH Block Grant is the Special Projects of Regional and National Significance (SPRANS). SPRANS funding complements and helps ensure the success of state Title V, Medicaid and the Children's Health Insurance Program (CHIP) by driving innovation, training young professionals and building capacity to create integrated systems of care for mothers and children. Examples of innovative projects funded through SPRANS include guidelines for child health supervision from infancy through adolescence (i.e. Bright Futures); nutrition care during pregnancy and lactation; recommended standards for prenatal care; successful strategies for the prevention of childhood injuries; and health safety standards for out of home child care facilities.

SPRANS grants are awarded to training programs at universities across the country including University of Alabama at Birmingham, University of Illinois, University of Oklahoma, University of Tennessee, University of Washington, Tulane University, Medical University of South Carolina and Johns Hopkins University. These institutions utilize SPRANS funding to prepare the next generation of maternal and child health leaders who will go on to serve in communities throughout the United States.

One of the most exciting developments with the Title V MCH Block Grant is a transformation that is happening right now under the leadership of Dr. Michael Lu, Associate Administrator of the Health Resources and Services Administration Maternal and Child Health Bureau. This transformation is focused on three main goals – to reduce burden, maintain flexibility and

improve accountability. At its center is an effort to improve our performance measurement framework with a sharpened focus on national outcome measures, national performance measures and evidence-based strategy measures.

This transformation ensures that investments made by the programs support evidence-based or informed strategies. Title V focuses on accountability and delivering results, and we are confident this transformation will build and strengthen that important focus so you can be assured that we are getting the best value for the taxpayer dollar while making real and measurable differences in the lives of our mothers and children. For more information on this effort, my staff will be happy to help arrange for further briefing and information on what this means for your state.

In our view, one of the biggest under-celebrated success stories of recent times are the contributions this committee makes in funding programs such as the Title V MCH Services Block Grant that contribute to substantial progress in reducing infant mortality.

Ensuring that babies are born in optimal health is all the more important considering the recent scientific advances in our understanding about how a baby's early years are critical to building a strong foundation for the rest of their life course. That is the good news – but there also are a few caveats and contradictions. First, there are persistent and unacceptable disparities among racial and ethnic groups that have existed since the data collection began. The black and Native American infant mortality rates are twice the rates of whites, and in some communities it is even three times higher.

The second caveat is that the political will to accelerate progress and eliminate disparities is inconsistent. Perhaps the biggest contradiction is that the United States spends more money on maternity care than any other nation on earth, yet still lags behind 26 other industrialized nations on the key outcome of infant mortality.

Part of the problem is that too often we spend more on high tech treatments – think elective C-sections and neonatal intensive care units – than on basic prevention programs to address risk factors that can lead to poor birth outcomes. For example, we know that breastfeeding, family planning, immunization, smoking cessation and safe sleep are effective in reducing infant mortality. However, funding levels for these key public health programs have never matched actual need, have slowly eroded over time, and are suffering further threats from budget caps and looming sequestration.

The Collaborative Improvement and Innovation Network (CoIIN) to Reduce Infant Mortality, funded in part by Title V SPRANS dollars, is a public-private partnership to reduce infant mortality and improve birth outcomes. Participants learn from one another and national experts, share best practices and lessons learned, and track progress toward shared benchmarks. Declines in infant mortality, non-medically indicated early term deliveries, the number of women smoking during pregnancy and preterm birth have already been observed in the 13 Southern states where the CoIIN began. These successes illustrate the return on investment in low-tech prevention efforts that can be realized through greater support for Title V.

Congress, of course, has the power of the purse, but has not consistently delivered on its obligation to annually review programmatic funding levels for public health programs and match resources to national needs. Currently funded at $638.2 million, one year of spending on the Title V MCH Block Grant preventive program represents just a half day's spending on the Medicaid program, which at $1.3 billion a day reached a total of $475 billion in 2014. This demonstrates once again that our health system spends plenty on health *care* but invests precious little in *prevention* and public health efforts. In terms of total potential cost savings to our health system, far too little attention is consistently given to health economics and the measurable financial impact of public health and the prevention of disease, illness and early death.

Finally, I would like to briefly mention the work being done by state Title V programs to respond to emerging public health issues such as Zika and the opioid use epidemic, both of which have direct implications for maternal and child health. You may be interested to know that Title V is already stepping in to conduct outreach and surveillance on Zika. In Puerto Rico, for example, the Title V Children with Special Health Care Needs program is providing clinical training and outreach to pediatric providers to ensure they are familiar with CDC guidelines and are able to evaluate infants with possible congenital Zika virus infection in accordance with those guidelines. Regarding opioid use, many state Title V programs are particularly involved with efforts to address neonatal abstinence syndrome (NAS). In Kentucky, the Title V agency has invested significant time working with other public health agencies to identify best practices for treatment options for women with substance use disorders, especially during pregnancy.

Unfortunately, both of these issues represent major threats to the health and wellbeing of our nation's women, children and their families. Therefore, I also urge the Appropriations Committee to act quickly on emergency supplemental funding packages in order to meet the full demands required to tackle both Zika and the opioid use epidemic.

Thank you again for your support in recent years to increase funding for the Title V MCH Block Grant. We hope to continue to build on recent successes and that you can support the $12 million increase in funding for the federal investment in the cost effective and accountable Title V MCH Block Grant.

About AMCHP: The Association of Maternal & Child Health Programs is a national resource, partner and advocate for state public health leaders and others working to improve the health of women, children, youth and families, including those with special health care needs.

Tuberculosis Roundtable
Nuala Moore
Associate Director of Government Relations
American Thoracic Society
1150 18th St. N.W., Suite 300
Washington, CD 20036
(202) 296.9770
Nmoore@thoracic.org

The TB Roundtable, a coalition of over 15 research, public health and health professional associations working to support global and domestic tuberculosis (TB) control and research, thanks Chairman Cole and Ranking Member DeLauro and fellow members of the committee for this opportunity to provide written testimony to discuss important health threats to our country and opportunities that lie within government to address them. Our testimony will outline the importance of TB research and development dollars to domestic public health preparedness. We recognize that you face many challenging decisions about expenditures but given the urgent need to address drug-resistant TB (DR-TB), we are writing to encourage you to prioritize anti-TB efforts. Specifically, we request that in any final version of Fiscal Year (FY) 2017 appropriations language, you strongly urge BARDA to include TB in their new emerging infectious disease efforts and invest in the development of new TB diagnostics, drugs and vaccines as part of the Combating Antibiotic Resistant Bacteria (CARB) initiative and the Emerging Infectious Disease program at BARDA.

TB causes more deaths than any other single infectious disease agent, with 9.6 million new illnesses and 1.5 million deaths in 2014. Approximately 480,000 of those cases were multidrug-resistant (MDR), including 9.7% that were extensively drug-resistant (XDR). Only about 10% of people with MDR-TB in 2014 were successfully treated, according to the World Health Organization.[i] While these statistics are alarming, even more concerning is the lack of research funding going towards new, improved tools and treatments for one of humanity's oldest diseases.

While Zika and Ebola have captured headlines and funding commitments, TB's domestic and global health impact is much more costly and deadly. Because TB is airborne, TB can be contracted by inhaling the bacteria when a person with active TB disease of the lungs or throat coughs or sneezes -- it's only necessary to inhale a few of these germs to become infected. The only available vaccine for TB, Bacille Calmette-Guérin (BCG), is only moderately effective in preventing TB in infants and young children – and it doesn't adequately protect teens and adults who suffer most of the disease burden. Current treatment regimens are long, expensive, and difficult to implement. Treatment side effects are serious and long-lasting, including permanent hearing loss. Even our current diagnostics are inadequate, with rapid, accurate drug susceptibility testing only available for just one TB drug out of the several required for an effective regimen.

TB does not just impact the rest of the world. Every state in the U.S. continues to report cases of TB each year and cases of TB occasionally make the news when diagnosed, with recent examples in Sturgis, Michigan;[ii] Marion, Alabama[iii], El Paso, Texas[iv]; or DeKalb County Georgia[v]. In March 2015, 27 people tested positive for TB in a high school located in Olathe, Kansas, prompting the testing of more than 300 students and staff[vi]. Last year, an individual

with XDR-TB was treated at the National Institutes of Health after traveling to and through the U.S. These travels included a long flight from India to Chicago, and then driving through Illinois, Tennessee, and Missouri, visiting friends and relatives, while infectious with a drug-resistant strain of this deadly airborne disease[vii]. Just a few weeks ago, the CDC released figures showing the first increase in TB cases domestically in 23 years[viii]. We know that TB anywhere can be TB everywhere.

Although the medical community has made strides to combat TB, the threat of this epidemic is growing, in part because of the spread of dangerous strains of MDR-TB and XDR-TB around the world, which we are trying to fight with 20th century technologies. While MDR-TB is resistant to at least two of the key front-line drugs used to treat TB, XDR-TB is resistant to nearly all current drug options. The costs to treat MDR- and XDR-TB are enormous. In the U.S., a case of MDR-TB costs about 15 times the amount that is needed to treat drug sensitive TB, often requiring 20-26 months of treatment. And treating a single case of XDR-TB could cost more than half a million dollars -- enough to wipe out a city's total public health budget for a year[ix]. Underscoring the urgent need for new tools to combat this disease, the CDC cited MDR and XDR-TB as serious antibiotic resistant threats in its 2013 report on antibiotic resistance in the U.S.

Efforts at BARDA are currently underway to establish an Emerging Infectious Disease Division to focus on naturally occurring infectious diseases. Including TB in BARDA's new emerging infectious disease efforts to invest in the development of a TB vaccine and new TB drugs and diagnostics as part of the CARB initiative and the Emerging Infectious Disease program will be a critical step to ensuring that new vaccine, treatment and diagnostic options are developed and available for use. We respectfully urge Congress to place more attention on the threat of TB and invest more time and resources in developing 21st century solutions to an age-old problem. As fortunate as we are to live in a nation that has the adequate infrastructure and resources to combat a host of disease threats, with TB we are leaving American and global citizens with outdated treatment to an ever-changing threat.

---

[i] The World Health Organization, 2015 *Global Tuberculosis Report*, Executive Summary, Page 1,
[ii] Sturgis Journal, *Case of Tuberculosis Treated in Sturgis*, Oct. 23, 2015, http://www.sturgisjournal.com/article/20151023/NEWS/151029514
[iii] The New York Times, *In Rural Alabama, Longtime Mistrust of Medicine Fuels a TB Outbreak*, Jan. 18, 2016, http://www.nytimes.com/2016/01/18/us/in-rural-alabama-a-longtime-mistrust-of-medicine-fuels-a-tuberculosis-outbreak.html?_r=0
[iv] KKTV, *El Paso County Jail Inmate Tests Positive for Latent TB*, Oct. 22, 2015, http://www.kktv.com/home/headlines/El-Paso-County-Jail-Inmate-Tests-Positive-For-Latent-Tuberculosis-335346171.html
[v] 11 Alive, *Student Tests Positive for TB at Dekalb Co. School*, Oct. 22, 2015, http://legacy.11alive.com/story/news/local/brookhaven/2015/10/22/student-tests-positive-tb-dekalb-co-school/74414390/
[vi] CBS News, *Tuberculosis Infects Dozens at Kansas High School*, March 28, 2015, http://www.cbsnews.com/news/tuberculosis-infects-dozens-at-kansas-high-school/
[vii] NBC News, *Exclusive: Patient With Extreme Form of TB Sent to NIH*, June 9, 2015, http://www.nbcnews.com/health/health-news/exclusive-patient-extreme-form-tb-sent-nih-n371806
[viii] Centers for Disease Control and Prevention (CDC), *Weekly Mortality and Morbidity Report*, March 25, 2016, http://www.cdc.gov/mmwr/volumes/65/wr/pdfs/mm6511a2.pdf
[ix] CDC, *Take on Tuberculosis Infographic*, 2015. http://www.cdc.gov/tb/publications/infographic/default.htm

Gina Gavlak, RN, Chair, National Advocacy Committee, American Diabetes Association
U.S. House Appropriations Subcommittee on Labor, Health, Human Services, and Related Agencies
Contact: Lisa Cox, Director, Federal Government Affairs, American Diabetes Association, lcox@diabetes.org

For Fiscal Year (FY) 2017, the American Diabetes Association (Association) urges the Subcommittee to deepen its investment in research and prevention to find a cure, and improve the lives of those living with, and at risk for, diabetes. We ask the Subcommittee to provide $2.165 billion for the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) at the National Institutes of Health (NIH), $170.129 million for the Division of Diabetes Translation (DDT) at Centers for Disease Control and Prevention (CDC), and $25 million for the National Diabetes Prevention Program (National DPP) at CDC.

Nearly 30 million Americans live with diabetes and 86 million Americans have prediabetes. I have been living with type 1 diabetes since was 10 years old. I remember listening as the doctor told my mom that I would never be able to have children and that diabetes would shorten my life. Thanks to the many medical discoveries and advancements at the NIH and translational research from CDC, I have proven her wrong. I have two beautiful, healthy children and have lived 36 years with diabetes, without complications.

I also remember a more recent conversation about diabetes with my family. Two years ago, my sister was diagnosed with type 1 diabetes at age 38. As we talked that day and I helped to console her and then connect her to the health care she would need to live with diabetes, I couldn't help but think how much farther we need to go to ensure that no one has to receive a diagnosis of diabetes again.

As a person living with diabetes who is also an emergency department nurse and president of a charitable clinic, I see the human and economic toll diabetes extracts from my patients and their families. The lives of people living with, and at risk for, diabetes are better because of NIH research and CDC prevention activities. Progress has been great, but much more must be done to stop diabetes and the devastating complications I see every day. I am proud to share my testimony with you on behalf of my sister, my patients, and the millions of American adults and children living with diabetes or prediabetes.

The diabetes epidemic is one of our country's biggest challenges and one touching all of our lives. According to the CDC, as many as one in three adults in our country – closer to one in two among minority populations – will have diabetes in 2050 if present trends continue. The sobering cost of this horrific disease is lived everyday by those who face blindness, suffer heart attacks and strokes, struggle with kidney failure and lose limbs, along with other deadly complications. Every year, 1.4 million Americans aged 20 years or older are diagnosed with diabetes. That means every 23 seconds someone in this country is diagnosed with diabetes. Today, diabetes will cause 200 Americans to undergo an amputation, 136 to enter end-stage kidney disease treatment, and 1,795 to develop severe retinopathy that can lead to vision loss.

In addition to the horrendous physical toll, diabetes is economically devastating to our country. A 2014 report found the total annual cost of diagnosed and undiagnosed diabetes, prediabetes, and

gestational diabetes in our country has skyrocketed by an astonishing 48% over 5 years – to $322 billion. People with diagnosed diabetes have health care costs 2.3 times higher than those without diabetes. One in three Medicare dollars is spent caring for people with diabetes. Despite the escalating cost of diabetes to our nation, the federal investment for diabetes research and programs at the NIH and CDC has not equaled the shocking pace of the diabetes epidemic. It doesn't have to be this way. America has the power to stop the diabetes epidemic and make the final chapter a success story for the ages. The state of our nation's diabetes epidemic justifies increased federal funding in FY2017 for diabetes research and prevention programs.

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 change food into energy. In people with diabetes, either the pancreas does not create insulin, which is type 1 diabetes, or the body does not create enough insulin and/or cells are resistant to insulin, which is type 2 diabetes. Diabetes results in too much glucose in the blood stream. Blood glucose levels that are too high or too low (as a result of medication to treat diabetes) can be life threatening in the short term. In the long term, diabetes is the leading cause of kidney failure, new cases of adult-onset blindness, and non-traumatic lower limb amputations, and a leading cause of heart disease and stroke. Additionally, up to 9.2% percent of women are affected by gestational diabetes, a form of glucose intolerance diagnosed during pregnancy placing both mother and baby at risk for complications and for type 2 diabetes. Those with prediabetes have higher than normal blood glucose levels and are at risk for type 2 diabetes, but can take action to lower that risk.

The National Institute of Diabetes and Digestive and Kidney Diseases at NIH

The American Diabetes Association requests funding for NIDDK of $2.165 billion in FY2017 to support groundbreaking research. Research at NIDDK has led to many discoveries helping Americans prevent or better manage diabetes. For example, people with diabetes now manage their disease with a variety of insulin formulations and regimens far superior to those used in decades past, which have reduced the risk for the serious complications of diabetes: heart disease, stroke, lower extremity amputation, blindness, and kidney disease. NIDDK research has led to the availability of tools to prevent life-threatening high and low blood glucose levels such as continuous glucose monitors and insulin pumps.

Further, the transformative Diabetes Prevention Program (DPP) at NIDDK showed individuals with prediabetes can lower their risk of developing type 2 diabetes by 58 percent through dietary changes and increased physical activity. Building on these results, the CDC, working with community, health care, and faith-based organizations, private insurers, employers, and government agencies has put this research into practice through the National Diabetes Prevention Program. The Centers for Medicare and Medicaid Services (CMS) has recognized the value of this approach to prevent type 2 diabetes and has proposed Medicare coverage of the National DPP. This would not have been possible without NIDDK's clinical trial.

Additional research is needed to build on these advancements. Diabetes researchers across the country are poised for further innovation to transform diabetes prevention and care. With FY 2017

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 expansion of NIDDK's comparative effectiveness clinical trial testing different medications to determine the best treatments for type 2 diabetes and continued development of the artificial pancreas, a closed looped system combining continuous glucose monitoring with insulin delivery. Additionally, the NIDDK would be able to move forward with research to improve the treatment of diabetic foot ulcers to reduce amputations, understand the relationship between diabetes and neuro-cognitive conditions like dementia and Alzheimer's disease, and discover how drugs to treat diabetes may help those facing heart disease and cancer.

The Division of Diabetes Translation at CDC

The federal government's role in coordinating efforts to prevent diabetes and its serious complications through the Division of Diabetes Translation and its evidenced-based, outcomes-focused diabetes programs is essential. In FY 2016, Congress recognized this by providing $170.129 million for DDT, whose mission is to eliminate the preventable burden of diabetes through research, education, and by translating science into clinical practice. DDT has a proven record of success in primary prevention efforts as well as programs to help those with diabetes manage their disease and avoid complications.

We urge Congress to again provide $170.129 million in FY2017. With these resources, the DDT will be able to continue diabetes prevention activities at the state and local levels. Funding will support these efforts through the State and Local Public Health Actions to Prevent Obesity, Diabetes, and Heart Disease grants, with a focus on improving prevention at the community and health system levels in populations with highest risk for diabetes. It will support basic and enhanced diabetes prevention efforts under the State Public Health Actions grant program for cross-cutting approaches to prevent and control diabetes, heart disease and stroke. It will also enable the DDT to expand its translational research activities to improve diabetes prevention, and continue its valuable diabetes surveillance work.

The National Diabetes Prevention Program at CDC

I am alarmed 86 million Americans have prediabetes and are on the cusp of developing type 2 diabetes. 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 five years. Managed by the CDC, the National Diabetes Prevention Program (National DPP) is a public-private partnership of community organizations, private insurers, employers, health care 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. First, community-based diabetes prevention sites where those at high risk for diabetes attend the intervention program. Second, a national recognition program coordinated by CDC to establish evidence-based standards for participating intervention sites, and provide the quality monitoring to ensure success. Third, public and health care 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. Fourth, informed referral networks so health care providers can refer patients with prediabetes to the local intervention sites.

Recently the Secretary of HHS announced that the CMS Office of the Actuary found that seniors participating in a National DPP program have Medicare costs that are $2,650 less than non-participants over a 15 month period. Through a demonstration project administered by the YMCA, we now know that this program not only improves health, but lowers health care costs and will have a valuable impact on our nation's economy. The Secretary will now take steps to implement coverage for this program as a Medicare benefit.

We urge Congress to provide $25 million for the National DPP in FY2017 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 critical program and continue to manage its recognition program to ensure sites follow the evidence-based curriculum and achieve the same high level of results.

Conclusion

We can and must change our country's story with regard to diabetes. We urge the Subcommittee's FY2017 appropriations decisions to reflect the necessity of taking action in light of the human and economic burden of this horrendous disease. The Association looks forward to working with you to stop diabetes.

Atul Malhotra, MD
President, American Thoracic Society
Nmoore@thoracic.org; (202) 296. 9770
1150 18th St, N.W. #300
Washington, DC 20036

STATEMENT OF
THE AMERICAN THORACIC SOCIETY
SUBMITTED TO
THE HOUSE LABOR, HEALTH AND HUMAN SERVICES, AND EDUCATION APPROPRIATIONS SUBCOMMITTEE
FISCAL YEAR 2017 LABOR, HEALTH AND HUMAN SERVICES, AND EDUCATION APPROPRIATIONS BILL
DEPARTMENT OF HEALTH AND HUMAN SERVICES

April 15, 2016

SUMMARY: FUNDING RECOMMENDATIONS (in millions $)

National Institutes of Health	$34,500
National Heart, Lung & Blood Institute	$3,400
National Institute of Allergy & Infectious Disease	$4,715
National Institute of Environmental Health Sciences	$732.2
Fogarty International Center	$70.7
National Institute of Nursing Research	$152
Centers for Disease Control and Prevention	$7,800
National Institute for Occupational Safety & Health	$339.1
Asthma Programs	$30.5
Div. of Tuberculosis Elimination	$243
Office on Smoking and Health	$220
National Sleep Awareness Roundtable (NSART)	$1

The ATS's 15,000 members help prevent and fight respiratory disease through research, education, patient care and advocacy.

LUNG DISEASE IN AMERICA
Respiratory diseases are the third leading cause of death in the U.S., responsible for one of every seven deaths. Diseases affecting the respiratory (breathing) system include chronic obstructive pulmonary disease (COPD), lung cancer, influenza, sleep disordered breathing, pediatric lung disorders, tuberculosis, occupational lung disease, asthma, and critical illness.

National Institutes of Health
The NIH is the world's leader in groundbreaking biomedical health research into the prevention, treatment and cure of diseases such as lung cancer, COPD and tuberculosis. But sequestration, annual funding cuts and a lack of inflationary adjustments over the past decade have eroded the NIH research budget. NIH's spending power in inflation-adjusted dollars has declined by over 20% since 2003. The number of grants supported by the NIH is now at the lowest level since 2001. The ATS is very concerned that due to reductions in federal research funding, there is a lack of opportunities for young investigators who represent the future of scientific innovation.

We ask the subcommittee to provide at least $34.5 billion in funding for the NIH in FY2017.

Despite the fact that lung disease is the third leading cause of death in the U.S., lung disease research is underfunded. The COPD death rate has doubled within the last 30 years and is still increasing, while the rates for the other top causes of death (heart disease, cancer and stroke) have decreased by over 50 percent. In FY2014, lung disease, critical illness and sleep research represented 27.3% of the National Heart Lung and Blood Institute's (NHLBI) budget. Despite the rising lung disease burden, research funding for the disease is a small fraction of the money invested for the other three leading causes of death. In order to stem the devastating effects of lung disease, research funding must continue to grow.

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 $7.8 billion for the CDC in FY2017.**

ANTIBIOTIC RESISTANCE

According to the Centers for Disease Control and Prevention's (CDC) 2013 report, *Antibiotic Resistance Threats in the United States,* as many as 23,000 deaths occur in the US annually due to antibiotic resistant bacterial and fungal pathogens including drug resistant pneumonia and sepsis infections. The rise of antibiotic resistance demonstrates the need to increase efforts through the CDC, NIH and other federal agencies to monitor and prevent antibiotic resistance and develop rapid new diagnostics and treatments. This includes the following recommendations for CDC programs:

- **$200 million for the Antibiotic Resistance Solutions Initiative**
- **$21 million for the National Healthcare Safety Network (NHSN)**
- **$30 million for the Advanced Molecular Detection (AMD) Initiative**

To address antibiotic resistance research needs, we urge the committee to provide $4,715 billion for the National Institutes of Allergy and Infectious Disease (NIAID) to spur research into rapid new diagnostics, new treatments and other activities and $512 million for the Biomedical Advanced Research and Development Authority (BARDA) to support antimicrobial research and development.

COPD

Chronic Obstructive Pulmonary Disease (COPD) is the third leading cause of death in the United States and the third leading cause of death worldwide, yet the disease remains relatively unknown to most Americans. CDC estimates that 12 million patients have COPD; an additional 12 million Americans are unaware that they have this life threatening disease. In 2010, the estimated economic cost of lung disease in the U.S. was $186 billion, including $117 billion in direct health expenditures and $69 billion in indirect morbidity and mortality costs.

The NHLBI is developing a national action plan on COPD, in coordination with the CDC to expand COPD surveillance, development of public health interventions and research on the

disease and increase public awareness of the disease and we urge Congress to support it. We also urge CDC to include COPD-based questions to future CDC health surveys, including the National Health and Nutrition Evaluation Survey (NHANES) and the National Health Information Survey (NHIS).

TOBACCO CONTROL

Tobacco use is the leading preventable cause of death in the U.S., responsible for one in five deaths annually. The ATS is pleased that the Department of Health and Human Services has made tobacco use prevention a top priority. 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. **In order to significantly reduce tobacco use within five years, as recommended by the subcommittee in FY2010, the ATS recommends a total funding level of $220 million for the Office of Smoking and Health in FY2017.**

ASTHMA

Asthma is a significant public health problem in the United States. Approximately 25 million Americans currently have asthma. In 2013, 3,388 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. The disease costs our healthcare system over $50.1 billion per year. African Americans have the highest asthma prevalence of any racial/ethnic group and the age-adjusted death rate for asthma in this population is three times the rate in whites. A study published in the *American Journal of Respiratory Critical Care* in 2012 found that for every dollar invested in asthma interventions, there was a $36 benefit. **We ask that the subcommittee's appropriations request for FY2017 that funding for CDC's National Asthma Control Program be maintained at a funding level of at least $30.596 million.**

SLEEP

Several research studies demonstrate that sleep-disordered breathing and sleep-related illnesses affect an estimated 50-70 million Americans. The public health impact of sleep illnesses and sleep disordered breathing is still being determined, but is known to include increased mortality, traffic accidents, cardiovascular disease, obesity, mental health disorders, and other sleep-related comorbidities. **The ATS recommends a funding level of $1 million in FY17 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 Nation Center for Sleep Disordered Research (NCSDR) at the NHLBI.

TUBERCULOSIS

Tuberculosis (TB) is the leading global infectious disease killer, ahead of HIV/AIDS, claiming 1.5 million lives each year. In the U.S., every state reports cases of TB annually and in 2015, the CDC reported the first national increase in TB cases in over 20 years. Drug resistant tuberculosis was identified as a serious public health threat to the U.S. in the CDC's 2013 report on antimicrobial resistance. Drug-resistant TB strains poses a particular challenge to domestic TB control due to the high costs of treatment, intensive health care resources and burden on patients.

Treatment costs for multidrug-resistant (MDR) TB, which is up to two years in length, range from $100,000 to $300,000. The continued global pandemic of this airborne infectious disease and spread of drug resistant TB demand that the U.S. strengthen our investment in global and domestic TB control and research to develop new TB diagnostic, treatment and prevention tools.

The Comprehensive Tuberculosis Elimination Act (CTEA, P.L. 110-392), enacted in 2008, reauthorized programs at CDC with the goal of putting the U.S. back on the path to eliminating TB. **The ATS recommends a funding level of $243 million in FY 2017 for CDC's Division of TB Elimination, as authorized under the CTEA, and urges the NIH to expand efforts to develop new tools to address TB. Additionally, in recognition of the unique public health threat posed by drug resistant TB, we urge BARDA to support research and development into new drug-resistant TB diagnostic, treatment and prevention tools.**

PEDIATRIC LUNG DISEASE

The ATS is pleased to report that infant death rates for various lung diseases have declined for the past ten years. In 2009, of the 10 leading causes of infant mortality, 4 were lung diseases or had a lung disease component. Many of the precursors of adult respiratory disease start in childhood. For instance, many children with respiratory illness grow into adults with COPD. It is estimated that 7.1 million children suffer from asthma. While some children appear to outgrow their asthma when they reach adulthood, 75 percent will require life-long treatment and monitoring of their condition. The ATS encourages the NHLBI and NICHD to sustain and expand research efforts to study lung development and pediatric lung diseases.

CRITICAL ILLNESS

The burden associated with the provision of care to critically ill patients is enormous, and is anticipated to increase significantly as the population ages. Approximately 200,000 people in the United States require hospitalization in an intensive care unit because they develop a form of pulmonary disease called Acute Lung Injury. Despite the best available treatments, 75,000 of these individuals die each year from this disease. This is the approximately the same number of deaths each year due to breast cancer, colon cancer, and prostate cancer combined. Investigation into diagnosis, treatment and outcomes in critically ill patients should be a priority, and the NIH should be funded and encouraged to coordinate investigation in this area in order to meet this growing national imperative.

FOGARTY INTERNATIONAL CENTER

The Fogarty International Center (FIC) provides training grants to U.S. universities to teach AIDS treatment and research techniques to international physicians and researchers. Because of the link between AIDS and TB infection, FIC has created supplemental TB training grants for these institutions to train international health professionals in TB treatment and research. **The ATS recommends Congress provide $70.7 million for FIC in FY2017, to allow expansion of the TB training grant program from a supplemental grant to an open competition grant.**

RESEARCHING AND PREVENTING OCCUPATIONAL LUNG DISEASE

As Congress considers funding priorities for Fiscal Year 2017, 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 Centers for Disease Control and Prevention (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.

OREGON STATE INDEPENDENT LIVING COUNCIL TESTIMONY

April 15, 2016

Prepared for:

- House Appropriations Subcommittee on Labor, Health and Human Services, Education, and Related Agencies
- Senate Appropriations Subcommittee on Labor, Health and Human Services, Education, and Related Agencies

My name is Tina Treasure, and I am the Executive Director of the Oregon State Independent Living Council (SILC) and am submitting this on behalf of the Chair and members of that body. We wish to acknowledge your commitment to assisting people with disabilities to actively participate in their communities, by investing in the Independent Living Program. Our ask in today's correspondence is for that you reaffirm your commitment by increasing funding for Centers for Independent Living (CILs) in the U.S. Department of Health and Human Services appropriations by $200 million, for a total of $301 million for the Independent Living line item in FY 2017. This would be a major step in increasing the availability of crucial services that CILs make available to the over 57 million Americans with disabilities

We fully support the National Council on Independent Living's (NCIL) testimony. They are the oldest cross-disability, national grassroots organization run by and for people with disabilities. NCIL's membership includes people with disabilities, Centers for Independent Living, Statewide Independent living Councils, and other disability rights organizations.

CILs are unique in that they operate according to a strict philosophy of consumer control, in which people with any type of disability, including people with mental, physical, sensory, cognitive, and developmental disabilities, of any age, directly govern and staff the Center. Each of the 365 federally funded Centers are unique because they are run by people with disabilities and reflect the best interest of each community individually. They are non-residential, community-based, non-profit organizations designed and operated by individuals with disabilities and provide five core services: advocacy, information and referral, peer support, independent living skills training and transition services that facilitate the transition of individuals with significant disabilities from nursing homes and other institutions to home and community-based residences with appropriate supports and services. Also included are assistance to individuals with significant disabilities who are at risk of entering institutions so that the individuals may remain in the community, and the transition of youth with significant disabilities to postsecondary life.

The funding we are asking you to provide is urgently needed by CILs to meet the current demand- including the addition of a fifth core service as authorized by WIOA. In FY 2010 funding for the IL Program was $103,716,000, and in FY 2016 funding for the IL Program is $101,183,000. That equals a loss of $2.5 million, not including adjusting for inflation. Increased funding should be reinvested from the billions currently spent to keep people with disabilities in costly Medicaid nursing homes and institutions and out of mainstream of society.

Beyond the direct services they provide, CILs seek ways to broadly change traditional service delivery in their communities and throughout the nation, including reform of the long term care system. For over 40 years, CILs have sought community based programs to assist people with all types of disabilities, across the lifespan, to remain in or return to their family and friends, in their homes and communities. When such services are delivered in an individual's home, rather than a costly nursing facility or other institution, the result is tremendous cost savings to Medicaid, Medicare and states, while enabling people with disabilities to become more independent, financially self-sufficient, and less reliant on long term government supports. Research has found that community-based services are significantly less expensive than nursing home placements.

As previously mentioned, the Workforce Innovation and Opportunity Act created a fifth core service for Centers: transition. We strongly supported the addition of this fifth core service, but additional funding is greatly needed to effectively carry it out. Funding these transition services will be critical to promoting effective employment outcomes, successful nursing home transition, and increased community participation for transitioning students. Current funding levels barely sustain day-to-day operations. CILs struggle to meet the demands of the community and provide leadership and common sense solutions. Without increased funds our vision to achieve full integration of people with disabilities in society will be undercut and taxpayers will continue to pay for costly Medicaid nursing homes and bear the economic impact of negative employment outcomes and continued dependence on programs that disincentive work and community involvement. CILs are an excellent service and a bargain for America. They keep people active and engaged in their communities, and they save taxpayer money.

Thank you for this chance to provide testimony. We are happy to partner with you to ensure that Americans with disabilities have the opportunity become active, contributing members of society.

Outside Witness Testimony – Fiscal Year 2017 Appropriations

Submitted by
Kate Moraras, Senior Program Director, kate.moraras@hepb.org
Hepatitis B Foundation

Prepared for
The United States House Committee on Appropriations
Subcommittee on Labor, Health and Human Services, Education, and Related Agencies

April 15, 2016

The Hepatitis B Foundation (HBF) appreciates the opportunity to submit testimony to the U.S. House Appropriations Subcommittee on Labor, Health and Human Services, and Education, and Related Agencies (LHHS) regarding the FY 2017 Appropriations bill. HBF is the nation's leading nonprofit organization dedicated to finding a cure for hepatitis B and improving the lives of those affected worldwide through research, education and patient advocacy. To expand its reach and impact, HBF established and co-chairs *Hep B United*, a national coalition of 30 community-based coalitions and national organizations to address and eliminate hepatitis B in the U.S. We are concerned funding to combat chronic viral hepatitis in the U.S. continues to be severely inadequate, and does not come close to reflecting the burden of disease. ***We therefore urge the Subcommittee to address the issue across several agencies and programs within its jurisdiction in order to help meet the goal of developing new and better treatments, to find a cure, and to reduce the incidence and transmission of the hepatitis B virus. Specifically, we urge the subcommittee to increase appropriations as follows:***

- **Health Resources and Services Administration (HRSA) Bureau of Primary Health Care: + $3 million**. This is necessary to demonstrate, test, and validate the most effective protocols to eliminate the perinatal transmission of hepatitis B.

- **Centers for Disease Control and Prevention (CDC): +$28.8 million.** This will permit a more comprehensive response to control the spread of acute and chronic hepatitis B infection through increased surveillance, testing, education, and linkage to care and treatment.
- **National Institutes of Health (NIH): + $2.4 billion in total including +$49 million for hepatitis B research.** This will permit a doubling of NIH research funding focused on finding a cure for HBV in a trans-Institute initiative guided by a professional judgment budget. NIH funding for HBV has actually decreased by almost 16% since FY 2011. These additional resources will put us on a path to find a cure. HBF joins with the Ad Hoc Group for Biomedical Research and requests at least $34.5 billion for the NIH in FY 2017.

Scope of the Epidemics

In the U.S., the CDC estimates that up to 5.7 million people are living with chronic hepatitis B virus (HBV) and hepatitis C virus (HCV) infection, and at least half of persons living with HBV or HCV do not know they are infected.[1] However, these are likely conservative estimates as surveillance systems are fragmented and underfunded. HBV and HCV are silent infections, and without early diagnosis or intervention, can lead to serious liver diseases and liver cancer. There are safe and highly effective vaccines and treatments to prevent and control HBV, and revolutionary curative treatments for HCV. Strategies to increase testing, vaccination, treatment and linkages to care, can dramatically reduce disease and premature deaths due to chronic viral hepatitis.

Hepatitis B and Liver Cancer

It is estimated that over 2 million Americans are living with chronic HBV infection, but only 25% are aware of their infection and less than 10% of infected individuals are able to access

[1] http://www.cdc.gov/hepatitis/abc/index.htm

care and receive treatment.[2] Chronic HBV infection disparately impacts and represents serious public health inequities for racial and ethnic communities. For example, Asian Americans and Pacific Islanders make up 5% of the total U.S. population, yet account for more than 50% of Americans living with chronic HBV infection.[3] Additionally, CDC found significant increases in acute HBV infections in Kentucky, Tennessee, and West Virginia, representing a 114% increase in acute HBV infections during 2009–2013.[4]

Left untreated, 1 in 4 of those with chronic HBV infection will die prematurely from liver failure and/or liver cancer. The CDC *2016 Annual Report to the Nation on the Status of Cancer* found that unlike other cancers, liver cancer incidence and death rates are rising. In the U.S., liver cancer is the second deadliest cancer with a 5-year survival rate of only 10%.[5] This underscores the urgent need for HBV screening to identify new and chronic infections. Furthermore, with the HBV vaccine that has been available for over 20 years, *preventing hepatitis B infections can prevent primary liver cancer.* HBV vaccination coverage, however, is low among adults; survey data indicated that coverage with at least three doses of HBV vaccine was 32.6% for adults aged 19–49 years, the group at highest risk for new infections.[6]

Elimination of Perinatal Hepatitis B Transmission

The transmission of HBV from mother to child during birth is the most common route of transmission worldwide. Despite prevention efforts, approximately 800 to 1,000 babies are born each year in the U.S. and develop a chronic HBV infection.[7] Without intervention, newborns exposed to HBV during delivery have a 90% risk of developing a chronic infection, and 25% of

[2] Cohen C, H. S., McMahon BJ, Block JM, Brosgart CL, Gish RG, London WT, Block TM. (2011). Is chronic hepatitis B being undertreated in the United States? Journal of Viral Hepatitis, 18, 377-383.
[3] http://www.cdc.gov/knowhepatitisb
[4] http://www.cdc.gov/mmwr/volumes/65/wr/mm6503a2.htm?s_cid=mm6503a2_e
[5] http://www.cdc.gov/cancer/dcpc/research/articles/arn_7512.htm
[6] http://www.cdc.gov/mmwr/preview/mmwrhtml/mm6404a6.htm
[7] https://blog.aids.gov/wp-content/uploads/Perinatal_HBV_Report_FINAL_12-21-15-508.pdf

infants chronically infected will die prematurely from HBV-related complications. Effective post-exposure prophylaxis can prevent perinatal HBV transmission with a success rate of more than 95%.[8]

HBF believes that the elimination of perinatal HBV transmission is within reach if resources are dedicated to strengthening surveillance/referral systems and enhancing prevention. We are pleased the HRSA Bureau of Primary Health Care (BPHC) has agreed to look at an evaluation of intervention strategies to eliminate perinatal HBV transmission in HRSA-funded health centers. However, a full evaluation of intervention strategies will require the training of health care professionals, followed by service delivery, data collection, and evaluation. We urge that BPHC's funding plans accommodate these components and sequence of activities.

Strengthening Surveillance and State/Local Capacity

A strong national surveillance system is critical towards understanding the true burden of disease, monitoring trends, outbreaks, and tracking progress in public health interventions. The current state of surveillance, especially to track chronic HBV infections, is sorely lacking and masks the true state of the epidemic in the U.S. Currently, the CDC funds merely five states and two cities to conduct enhanced chronic viral hepatitis surveillance. CDC also provides resources to state and local health agencies through the Viral Hepatitis Prevention Coordinator Program (VHPC).[9] The VHPC program, which funds a prevention coordinator, is the only dedicated effort at a state/local level to coordinate viral hepatitis prevention activities. This position is severely underfunded and rarely enough to address HBV or HCV full time. We must increase state, local, and territorial capacity to address these epidemics and strengthen coordination, including surveillance, across the country.

[8] Ibid.
[9] http://www.cdc.gov/hepatitis/partners/vhcp.htm

Research for a Cure

We depend upon the NIH to fund research that will lead to new and more effective interventions to treat people with HBV and liver cancer. We thank the Committee for their continued investment in the NIH, and specifically for the robust $32.1 billion of funding in FY 2016. Sustaining increases for NIH is essential for development of life changing cures, pioneering treatments, and innovative prevention strategies.

Additional funding could make transformational advances in research leading to curative treatments for HBV. In view of the scope of the epidemic, it is disappointing that funding for HBV research at NIH has declined by almost 16% since FY 2011. Despite this decline, there is the greatest momentum for discovery. It is now possible to study the entire HBV life cycle and identify targeted vulnerabilities that can be exploited to cure this deadly disease. In order to take advantage of this new scientific opportunity, funding for HBV research should be doubled with the goal of discovering more effective treatments and finding a complete cure.

HBF also requests a stronger focus on liver cancer at the National Cancer Institute and urges the funding of a series of Specialized Programs of Research Excellence (SPOREs) focused on liver cancer. While SPOREs exist for every other major cancer, none currently exist that are focused on liver cancer.

Summary

We must make the elimination of chronic viral hepatitis in the U.S. a priority. We strongly urge the Subcommittee to increase the appropriation for HRSA/BPHC (+$3 million); the CDC Division of Viral Hepatitis (+$28.8 million); and for NIH (+$2.4 billion including +$49 million for hepatitis B research). We thank Chairman Cole, Ranking Member DeLauro, and members of the Subcommittee for their consideration of our testimony and request.

Testimony for the Labor, Health and Human Services Appropriations Subcommittee
U.S. House of Representatives
Kim Gandy, President and CEO, National Network to End Domestic Violence
Family Violence Prevention and Services Act (FVPSA) and related programs (HHS/ACF/CDC)
April 15, 2016

Labor, Health and Human Services Appropriations Subcommittee Chairman Cole, Ranking Member DeLauro, Chairman Rogers, Ranking Member Lowey and distinguished members of the Appropriations Committee, thank you for this opportunity to submit testimony on the importance of investing in Family Violence Prevention and Services Act (FVPSA) and Violence Against Women Act (VAWA) programs. I sincerely thank the Committee for its ongoing support for these lifesaving programs. We are grateful the increase allocated to FVPSA in FY16.

I am the President and CEO of the National Network to End Domestic Violence (NNEDV), the nation's leading voice for domestic violence survivors and their advocates. We represent the 56 state and territorial domestic violence coalitions, their nearly 2,000 member domestic violence and sexual assault programs, and the millions of victims they serve. Our direct connection with victims and victim service providers gives us a unique understanding of their needs and the vital importance of continued federal investments. I am submitting this testimony to request a targeted investment of **$260 million** in Family Violence Prevention and Services Act (FVPSA), Violence Against Women Act (VAWA) and related programs administered by the U.S. Department of Health and Human Services FY 2017 Budget (specific requests detailed below).

*** Incidence, Prevalence, Severity and Consequences of Domestic and Sexual Violence.** The crimes of domestic and sexual violence are pervasive, insidious and life-threatening. Recently, the Centers for Disease Control and Prevention (CDC) released the first-ever National Intimate Partner and Sexual Violence Survey (NISVS) which found that domestic violence, sexual violence, and stalking are widespread. Domestic violence affects more than 12 million people each year and nearly three in ten women and one in four men have experienced rape, physical, violence, or stalking in his or her lifetime.

Female victims of rape, physical violence, or stalking by an intimate partner experienced severe impacts such as fear, concern for their safety, need for medical care, injury, need for housing services, and missing work or school.

The CDC has estimated that 697,000 women in Oklahoma and 462,000 women in Connecticut have experienced rape, physical violence, or stalking by an intimate partner in their lifetime.[i] The terrifying conclusion of domestic violence is often murder, and every day in the United States, an average of three women are killed by a current or former intimate partner.[ii] The cycle of intergenerational violence is perpetuated as children are exposed to violence. Approximately 15.5 million children are exposed to domestic violence every year.[iii] One study found that men exposed to physical abuse, sexual abuse and witnessing adult domestic violence as children were almost 4 times more likely than other men to have perpetrated domestic violence as adults.

In addition to the terrible cost domestic and sexual violence have on the lives of individual victims and their families, these crimes cost taxpayers and communities. The cost of intimate partner violence exceeds $5.8 billion each year, $4.1 billion of which is for direct health care services.[iv] Translating this into 2016 dollars, based on the Bureau of Labor Statistics Consumer Price Index, the annual cost to the nation is over $9 billion per year. Domestic violence costs U.S. employers an estimated $3 to $13 billion annually.[v]

Despite this grim reality, we know that when a coordinated response is developed and immediate, and essential services are available, victims can escape from life-threatening violence and begin to rebuild their lives. To address unmet needs and build upon its successes, FVPSA and VAWA programs should receive significant increases in the FY '17 Labor, Health and Human Services Appropriations bill.

*** Family Violence Prevention and Services Act (FVPSA) (Administration for Children and Families) – $175 million request.** Since its passage in 1984 as the first national legislation to address domestic violence, FVPSA has remained the only federal funding directly for shelter programs. Now in its 32nd year,

FVPSA has made substantial progress toward ending domestic violence. Despite the progress and success brought by FVPSA, an unconscionable need remains for FVPSA-funded victim services.

There are more than 2,000 community-based domestic violence programs for victims and their children (approximately 1,500 of which are FVPSA-funded through state formula grants). These programs offer services such as emergency shelter, counseling, legal assistance, and preventative education to millions of adults and children annually and are at the heart of our nation's response to domestic violence. A 2008 multi-state study conclusively shows that the nation's domestic violence shelters are addressing victims' urgent and long-term needs and are helping victims protect themselves and their children.

This same study found that, if shelters did not exist, the consequences for victims would be dire, including "homelessness, serious losses including [loss of] children [or] continued abuse or death."[vi] Additionally, non-residential domestic violence services are essential to addressing victims' needs. Such programs provide a wide variety of services to victims including counseling, child care, financial support, and safety planning. Without the counseling services she received from her local domestic violence program, one victim said, "I would not be alive, I'm 100 percent certain about that."[vii]

*** The Increased Need for Funding: to Maintain Programs and Bridge the Gap.** Many programs across the country use their FVPSA funding to keep the lights on and their doors open. We cannot overstate how important this funding is: victims must have a place to flee to when they are escaping life-threatening violence. As increased training for law enforcement, prosecutors and court officials has greatly improved the criminal justice system's response to victims of domestic violence, there is a corresponding increase in demand for emergency shelter, hotlines and supportive services. Additionally, demand has increased as a result of the economic downturn, and victims with fewer personal resources become increasingly vulnerable. Since the economic crisis began, eight out of ten domestic violence shelters have reported an

increase in women seeking assistance from abuse.[viii] As a result, shelters overwhelmingly report that they cannot fulfill the growing need for these services.

Each year NNEDV releases a report entitled *Domestic Violence Counts: A 24-hr National Census of Domestic Violence Services (Census)*. The report revealed that in just one day in 2015, while 71,828 victims of domestic violence received services, over 12,197 requests for services went unmet, due to lack of funding and resources. Of those unmet requests, 63% were for safe shelter. In 2015, domestic violence programs reported that they had laid off nearly 1,235 staff positions in addition to reducing or eliminating 1,936 services in the past year, including prevention services, therapy, and child welfare advocacy. I strongly encourage you to read NNEDV's DV Counts Census (www.nnedv.org/census) to learn more about the desperate needs of victims state-by-state and nationally.

In 2013, domestic violence programs funded by the Family Violence Prevention & Services Act (FVPSA) provided shelter and nonresidential services to more than 1.3 million victims. Due to lack of capacity, however, an additional 186,552 requests for shelter went unmet. Since 2011, at least 19 local domestic violence programs across the country have been forced to close entirely.

For those individuals who are not able to find safety, the consequences can be extremely dire, including continued exposure to life-threatening violence or homelessness. It is absolutely unconscionable that victims cannot find safety for themselves and their children due to a lack of adequate investment in these services. In order to help meet the immediate needs of victims in danger and to continue this work to prevent and end domestic violence, FVPSA funding must be increased to its authorized level of $175 million.

ADDITIONAL REQUESTS

National Domestic Violence Hotline (Administration for Children and Families) – $12 million;

DELTA Prevention Program (Centers for Disease Control and Injury Prevention) – $6 million;

Rape Prevention and Education (RPE) (Centers for Disease Control and Injury Prevention) – $50 million;

Preventative Health and Health Services Block Grant, Rape Set-Aside – $7 million;

Violence against Women Health Initiative, (Office On Women's Health) - $10 million

---

[i] Black, M.C., Basile, K.C., Breiding, M.J., Smith, S.G., Walters, M.L., Merrick, M.T., Chen, J., & Stevens, M.R. (2011). The National Intimate Partner and Sexual Violence Survey (NISVS): 2010 Summary Report. Atlanta, GA: National Center for Injury Prevention and Control, Centers for Disease Control and Prevention.

[ii] Bureau of Justice Statistics (2008). Homicide Trends in the U.S. from 1976-2005. U.S. Dept. of Justice.

[iii] McDonald, R., et al. (2006). "Estimating the Number of American Children Living in Partner-Violence Families." *Journal of Family Psychology, 30(1)*, 137-142.

[iv] National Center for Injury Prevention and Control. *Costs of Intimate Partner Violence Against Women in the United States.* Atlanta (GA): Centers for Disease Control and Prevention; 2003.

[v] Bureau of National Affairs Special Rep. No. 32, Violence and Stress: The Work/Family Connection 2 (1990); Joan Zorza, *Women Battering: High Costs and the State of the Law*, Clearinghouse Rev., Vol. 28, No. 4, 383, 385.

[vi] Lyon, E. & Lane, S. (2009). Meeting survivors' needs: A multi-state study of domestic violence shelter experiences. Harrisburg, PA: National Resources Center on Domestic Violence.

[vii] Lyon, Eleanor, Bradshaw, Jill, Menard, Anne. *Meeting Survivors' Needs through Non-Residential Services & Supports: Results of a Multi-State Study*. Harrisburg, PA: National Resource Center on Domestic Violence. November, 2011.

[viii] *Mary Kay's Truth About Abuse Report*. Mary Kay Inc. (2012).

Prevent Blindness
Testimony to the House Appropriations Labor, Health and Human Services, Education, and Related Agencies Subcommittee
Submitted by: Hugh Parry, President & CEO, Prevent Blindness
April 15, 2016

Funding Request Overview

Prevent Blindness appreciates the opportunity to submit testimony to the Subcommittee and respectfully requests the following allocation and support in Fiscal Year (FY) 2017 to help promote eye health and prevent eye disease and vision loss:

- **Provide $1,500,000 to strengthen the Vision Health at the Centers for Disease Control and Prevention (CDC).**

- **Support the Maternal and Child Health Bureau's (MCHB) National Center for Children's Vision and Eye Health.**

Introduction and Overview

Prevent Blindness – the nation's leading non-profit, voluntary organization committed to preventing blindness and preserving sight – maintains a long-standing commitment to working with policymakers at all levels of government, organizations and individuals in the eye care and vision loss community, and other interested stakeholders to develop, advance, and implement policies and programs that prevent blindness and preserve sight.[1]

Vision-related conditions affect people across the lifespan. Good vision is an integral component to health and well-being. It affects virtually all activities of daily living and impacts individuals physically, emotionally, socially, and financially. Loss of vision can have a devastating impact on individuals and their families. An estimated 80 million Americans have a potentially blinding eye disease, three million have low vision, more than one million are legally blind, and 200,000 are more severely visually blind. Vision impairment in children is a common condition that affects five to ten percent of preschool age children, and is a leading cause of impaired health in childhood. Recent research showed that the economic burden of vision loss and eye disorders is $139 billion each year, $47.4 billion of which is federal spending. Alarmingly, while half of all blindness can be prevented through education, early detection, and treatment, the National Eye Institute (NEI) reports that "the number of Americans with age-related eye disease and the vision impairment that results is expected to double within the next three decades."[2]

To curtail the increasing incidence of vision loss in America, and its accompanying economic burden, Prevent Blindness advocates sustained and meaningful federal funding for programs that promote eye health and prevent eye disease, vision loss, and blindness; needed services and increased access to vision screening; and vision and eye disease research. In a time of significant fiscal constraints, we recognize the challenges facing the Subcommittee and urge you to consider the ramifications of decreased investment in vision and eye health. Vision loss is often preventable, but without continued efforts to better understand eye conditions, and their treatment, through research to develop the public health systems and infrastructure to disseminate and implement good science and

---

[1] For more information about Prevent Blindness and our federal government relations and public policy efforts, please visit www.preventblindness.org.

[2] "Vision Problems in the U.S.: Prevalence of Adult Vision Impairment and Age-Related Eye Disease in America," Prevent Blindness America and the National Eye Institute, 2008.

prevention strategies, millions of Americans face the loss of independence, loss of health, and the loss of their livelihoods, all because of the loss of their vision.

Vision and Eye Health at the CDC: Helping to Save Sight and Save Money

The CDC serves a critical role in promoting vision and eye health. Since 2003, the CDC and Prevent Blindness have collaborated with other partners to create a more effective public health approach to vision loss prevention and eye health promotion. The CDC works to promote eye health and prevent vision loss; improve the health and lives of people living with vision loss by preventing complications, disabilities, and burden; reduce vision and eye health related disparities; and integrate vision health with other public health strategies. However, severely constrained financial resources have limited the CDC's ability to take the work of the Vision Health Initiative (VHI) to the next level.

Prevent Blindness requests at least $1,500,000 in FY 2017 to strengthen vision and eye health efforts of the CDC. This funding level would allow the VHI to increase vision impairment and eye disease surveillance efforts, apply previous CDC vision and eye health research findings to develop effective prevention and early detection interventions, and begin to incorporate vision and eye health promotion activities into state and national public health chronic disease initiatives, with an initial focus on early detection of diabetic retinopathy.

In addition, the CDC engaged the Institute of Medicine (IOM) at the National Academies of Sciences, Engineering, and Medicine to study public health approaches to reduce vision impairment and improve eye health. The IOM will release a report in FY 2016 that captures findings from the study, and funding within this request would be allocated to support the implementation of the Academy's recommendations for CDC.

Investing in the Vision of Our Nation's Most Valuable Resource - Children

While the risk of eye disease increases after the age of 40, eye and vision problems in children are of equal concern. If left untreated, they can lead to permanent and irreversible visual loss and/or cause problems socially, academically, and developmentally. Although more than 12.1 million school-age children have some form of a vision problem, only one-third of all children receive eye care services before the age of six.[3] Vision disorders are among the leading cause of impaired health in childhood as 1 in 4 school-aged children has a vision problem significant enough to affect learning. But early detection can help prevent vision loss and blindness and understands many serious ocular conditions in children are treatable if diagnosed at an early stage.

In 2009, the MCHB established the National Center for Children's Vision and Eye Health (the Center), a national vision health collaborative effort aimed at developing the public health infrastructure necessary to address issues surrounding children's vision screening.

The Center has established a National Advisory Committee to provide recommendations toward national guidelines for quality improvement strategies, vision screening and developing a continuum of children's vision and eye health. With this support the Center, will continue to: (1) provide national leadership in dissemination of best practices,

[3] "Our Vision for Children's Vision: A National Call to Action for the Advancement of Children's Vision and Eye Health, Prevent Blindness America." Prevent Blindness America. 2008.

infrastructure development, professional education, and national vision screening guidelines that ensure a continuum of vision and eye health care for children; (2) advance state-based performance improvement systems, screening guidelines, and a mechanism for uniform data collection and reporting; and (3) provide technical assistance to states in the implementation of strategies for vision screening, establishing quality improvement measures, and improving mechanisms for surveillance.

Therefore, Prevent Blindness encourages the Subcommittee to support the work of the Center which, through partnerships, sound science, and targeted policy initiatives, promotes vision and eye health for the nation's children.

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 FY 2017 funding for the CDC Vision Health Initiative, 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. Please feel free to contact us at any time; we are happy to be a resource to Subcommittee members and your staff. We very much appreciate the Subcommittee's attention to – and consideration of – our requests.

Harold Wimmer
National President and CEO
American Lung Association
202-785-3355
Erika.Sward@Lung.org

FY 2017
American Lung Association
U.S. Senate Committee on Appropriations
Subcommittee on Labor, Health and Human Services, and Education
Department of Health and Human Services

Centers for Disease Control and Prevention (CDC)
Increase CDC funding to $7.8 billion
Office on Smoking and Health – $220 million
National Asthma Control Program– $30.596 million
Climate and Health Program – $18.613 million
Environment and Health Tracking Network – $35 million
Tuberculosis Programs – $243 million
CDC influenza planning and response – $187.558 million
NIOSH – $522.3 million
Prevention and Public Health Fund – Please Protect the Fund

National Institutes of Health (NIH)

The American Lung Association is pleased to submit its recommendations for Fiscal Year 2017 (FY17) 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 $34.5 billion for the National Institute of Health (NIH). We need sustained and robust investments for NIH so that the promise of biomedical research can be achieved. While our focus is on lung disease research, we support robust, sustained and predictable investments in research funding across the entire NIH with particular emphasis on the National Cancer Institute, the National Heart, Lung and Blood Institute, the National Institute of Allergy and Infectious Diseases, the National Institute of Environmental Health Sciences, the National Institute of Nursing Research, the National Institute on Minority Health & Health Disparities, the National Institute on Drug Abuse and the Fogarty International Center.

Lung Disease
Lung disease is the third highest killer in America. It takes the lives of almost 419,000 Americans each year, and is responsible for one in every six deaths. It has been estimated that more than 33 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 programs that provide resources for those who want to quit smoking, support groups for lung cancer patients, and classes that educate people on ways to avoid asthma attacks. 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 224,390 new cases of lung cancer will be diagnosed in 2016, and over 156,000 Americans will die from the disease – 85,710 in men and 70,542 in women. Survival rates for lung cancer tend to be lower than those of 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. Personalized and targeted therapies hold tremendous potential in the fight against lung cancer. As the result of previous investments in biomedical research, in 2015, the Food and Drug Administration approved seven new medications for patients with metastatic lung cancer. The American Lung Association thanks the Committee for its 5 percent increase in funding for NIH, including funds for the President's Precision Medicine Initiative with its ALCHEMIST and Lung-MAP trials that target lung cancer. **We ask the Committee to continue to build on this momentum by increasing funding for the National Institutes of Health to $34.5 billino in Fiscal Year 2017.**

Tobacco Use
The use of tobacco is the number one preventable cause of death in the United States. It kills approximately half a million people every year. 40 million American adults smoke and 4.7 million children use tobacco products. Annual health care and lost productivity costs total $332 billion in the U.S. each year. Each day, over 2,500 kids under 18 years of age try their first cigarette and close to 600 kids become new, regular daily smokers.

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 $220 million be appropriated to OSH for FY17.**

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 five 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

24 million Americans have asthma, including 6.3 million children. It is highly prevalent and a costly disease. The nation is making progress to combat against asthma but this advancement can only continue with sustained investment. Asthma prevalence rates are over 45 percent higher among African Americans than whites. Asthma costs our healthcare system over $50.1 billion annually and indirect costs from lost productivity add another $5.9 billion, for a total of $56 billion dollars annually.

The American Lung Association thanks the Committee for its increase in FY16 and **asks to appropriate $30.596 million to the CDC's National Asthma Control Program (NACP) in FY2017.** 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 23 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 27 states and the District of Columbia.

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

Chronic Obstructive Pulmonary Disease (COPD)

COPD is the third leading cause of death in the U.S. More than 24 million U.S adults had evidence of impaired lung function, indicating an under diagnosis of COPD. In 2013, 145,575 people in the U.S. died of COPD, representing one COPD death every 4 minutes. The American Lung Association also asks the Committee to continue its support of the National Heart, Lung and Blood Institute working with the 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.**

Pneumonia and Influenza

In 2013, there were a combined 56,979 deaths due to pneumonia and influenza combined. While other infectious diseases may receive much more public attention, a moderate flu epidemic could result in hundreds of thousands of deaths in the U.S. To prepare for a potential pandemic, **the American Lung Association supports funding the federal CDC Influenza efforts of at least $187.558 million.**

Tuberculosis (TB)
TB, an airborne infectious disease, is now the leading global infectious killer, ahead of HIV/AIDS, causing 1.5 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.

Drug resistant TB poses a particular challenge to TB control due to the high costs of treatment and intensive health care 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. The U.S. had 17 cases of extensively XDR- TB between 2008 and 2015.

Funding for CDC's national TB program has been cut back to the FY2005 level. We are deeply concerned that this funding level is eroding state TB programs and leaving communities vulnerable to TB, including drug resistant TB. **We request that Congress increase funding for tuberculosis programs at CDC to $243 million for FY 2017.**

Impact of Climate Change on Lung Health
CDC's Climate and Health Program is the only HHS program devoted to identifying the risks and develop effective responses to the health impacts of climate change, including worsening air pollution; diseases that emerge in new areas; stronger and longer heat waves; 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 $10 million for the Center for Disease Control and Prevention's Climate and Health Program**.

Conclusion
Lung disease remains a growing problem in the United States and is leading the nation as the third highest killer. There has 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. Significant strides must be taken to combat the lung disease. The level of support this committee approves for lung disease programs should be reflective of the urgency and magnitude 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. The Lung Association is appreciative of your support and we thank you for your consideration of our recommendations.

Testimony of Mr. James Lacy, Chairman
Rotary International's Polio Eradication Advocacy Task Force for the United States

Chairman Cole, members of the Subcommittee, Rotary International appreciates this opportunity to submit testimony to the Subcommittee on Labor, Health and Human Services, and Education, and Related Agencies in support of the polio eradication activities of the U. S. Centers for Disease Control and Prevention (CDC). The Global Polio Eradication Initiative (GPEI) 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 end polio forever. Rotary International supports the President's FY2017 request of $174 million for the polio eradication activities of the CDC to fully implement the polio eradication strategies outlined in the *Polio Eradication and Endgame Strategic Plan.*

PROGRESS IN THE GLOBAL PROGRAM TO ERADICATE POLIO

Thanks to this committee's funding for the fiscal year 2016 polio eradication activities of the CDC:

- There were fewer cases of polio in fewer places than in any point in history. Only 74 cases were confirmed for the entire year of 2015 – a decrease of more than 80% over 2014 levels. Only two countries – Pakistan and Afghanistan – confirmed cases of wild polio in 2015.
- There have been no cases of polio on the African continent since August of 2014.
- Nigeria was removed from the list of endemic countries in September 2015 following more than a year without a case of wild polio.
- Polio immunization campaigns reaching more than 400 million children were conducted in more than 30 countries, primarily in Africa, South Asia and the Middle East.
- Polio outbreaks in the Middle East, Horn of Africa, and Central Africa, which accounted for roughly 60% of all cases in 2013, have been brought under control. All polio free countries remain at risk for outbreaks until the wild poliovirus has been eradicated in the remaining places where it persists.
- The Global Polio Eradication Initiative is cautiously optimistic that type 3 polio may have been eradicated. There have been no cases of type 3 polio since November 2012.
- While the program works to ensure no child is ever paralyzed again by wild polio, it is also taking steps to stop rare instances of vaccine-derived polio cases by beginning the withdrawal of the oral polio vaccine and the global introduction of the inactivated polio vaccine, which carries no risk of paralysis.

The United States has been the leading public sector donor to the Global Polio Eradication Initiative. Rotary International appreciates the United States' generous support and recognizes increased funding provided by Congress in FY2016 to ensure the GPEI can fully implement the plan. Rotarians are committed to continuing their own fundraising for the program until the world is certified polio free. Rotarians will also continue to advocate support from the public and other governments, both polio free and polio affected, to support the successful execution of the *Strategic Plan.* The ongoing support of donor countries, like the United States, is essential to ensure the necessary human and financial resources are made available to polio-endemic and at risk countries to certify the world polio free.

Global polio eradication is Rotary International's top priority. Rotary's global membership of over 1.2 million business and professional leaders (more than 336,000 of which are in the U.S.) has contributed more than US$1.5 billion toward a polio free world. Rotary also leads the United States Coalition for the Eradication of Polio, a group of committed child health advocates that includes the March of Dimes Foundation, the American Academy of Pediatrics, the Task Force for Global Health, the United Nations Foundation, and the U.S. Fund for UNICEF.

CDC's vital role in Global Polio Eradication progress
Rotary commends CDC for its leadership in the global polio eradication effort, and greatly appreciates the Subcommittee's increased support of CDC's polio eradication activities to support full implementation of the *Strategic Plan*. The United States is the leader among donor nations in the drive to eradicate this crippling disease. CDC has used the Congressional support to make the following significant programmatic contributions:

Globally:

- With funding from FY 2015, CDC provided:
    - $33.9 million to UNICEF for approximately 100 million doses of oral polio vaccine, 6.9 million doses of inactivated polio vaccine, and $6.3 million for operational costs for NIDs in all polio-endemic countries and other high-risk countries in Asia, the Middle East and Africa. Most of these NIDs would not take place without the assurance of CDC's support.
    - $52.2 million to WHO for surveillance, technical staff and immunization activities' operational costs, primarily in Africa.
    - CDC Atlanta-based staff spent 2,360 person-days during 295 deployments providing technical assistance to global headquarters of partners, countries and regional offices on polio. Through April 2016, CDC Atlanta-based staff provided 1,352 person-days of technical assistance on 169 deployments to global headquarters of partners, countries and regional offices on polio.
- CDC's Stop Transmission of Polio (STOP) program trains and deploys public health professionals to improve vaccine-preventable disease surveillance and to help plan, implement, and evaluate vaccination campaigns. STOP places staff resources in countries of higher-risk for poliovirus transmission to support critical national immunization functions. STOP has trained and deployed more than 1,800 public health professionals to work on polio surveillance, data management, campaign planning and implementation, program management, and communications in high-risk countries. In 2015, the STOP program sent 247 professionals on 379 assignments to 42 countries.
- The CDC Director serves as the Chari of the Polio Oversight Board (POB), the top governance body for the Global Polio Eradication Initiative. The CDC also houses the Secretariat for the POB in support of the Director's role as POB Chair. This involves coordination across the highest levels of the Global Polio Eradication Initiative partnership.
- The CDC led efforts to coordinate the switch from trivalent oral polio vaccine to bivalent vaccine, scheduled to occur in April 2016. At the same time, CDC continues to work with

partners to help all countries introduce one dose of inactivated polio vaccine to their routine schedules by the last quarter of 2017.

- The CDC also supports global polio eradication by participating in technical advisory groups, EPI manager and other key global meetings. The CDC also published 27 articles on the progress toward polio eradication in the Morbidity and Mortality Weekly Report (MMWR) and in peer-reviewed journals.

Build capacity in Nigeria.

- The National Stop Transmission of Polio (N-STOP) program, adapted from the original STOP Program, has provided Nigeria with an accessible, flexible, and culturally competent workforce at the front lines of public health. N-STOP includes participatory training for public health workers composed of ten modules covering poliomyelitis, vaccine management and monitoring, program management, and problem-solving practices. CDC's National STOP program for Nigeria trained 219 staff at the Local Governing Area level in the highest risk states, playing 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.

Build capacity in Pakistan.

- In collaboration with the Pakistan Ministry of Health and in coordination with WHO and the USAID's mission in Islamabad, 64 national epidemiologists from CDC's Field Epidemiology Training Program (FETP) were trained and deployed to the highest risk districts for circulation of wild polio virus to help improve the quality of surveillance and immunization activities.

Improve program management and efficiency:

- Based on best practices developed in India and Nigeria, CDC established several important benchmarks to improve the performance of polio programs and to achieve greater efficiency. These benchmarks streamline decision making for program officials, by making clear who is accountable for achieving results while empowering program officials to respond rapidly to events on the ground.

- CDC also guided the establishment of Emergency Operations Centers (EOCs) and guided use of CDC-developed dashboards through the country and state levels. These have directly contributed to the dramatic turnaround in program quality in Nigeria and Pakistan.

Ensure high quality global surveillance:

- CDC provided (and continues to provide):
    - expertise in virology, diagnostics, and laboratory procedures, including quality assurance, and genomic sequencing of samples obtained worldwide.
    - training for virologists from around the world in advanced poliovirus research and public health laboratory support. CDC's Atlanta laboratories serve as a global reference center and training facility.
    - the largest volume of operational (poliovirus isolation) and technologically sophisticated (genetic sequencing of polio viruses) lab support to the 145 laboratories of the global polio laboratory network. CDC has the leading specialized polio reference lab in the world.

- 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.

Foster the effective transition of Global Polio Eradication assets

- CDC is leading 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, surveillance, outbreak response and bio containment, will be in place post-eradication. Presently, the global polio eradication staff is the single largest source of external technical assistance for immunization and surveillance in low-income countries, and polio eradication efforts are responsible for reaching the world's most vulnerable children with vaccines and other health interventions.

FY2017 budget request

For Fiscal Year 2017, we request this subcommittee to provide $174 million for the CDC's polio eradication activities, the level that was requested in the President's budget. This will allow CDC to provide to continue to build capacity to support intense supplementary immunization activities in polio-affected and at-risk countries, to develop leadership on data management and evidence-based decision making, and to implement for effective management and accountability. These funds will also help maintain essential certification standard surveillance. Finally, continued funding will enable CDC to capitalize on polio eradication efforts to strengthen immunization systems and protect the gains made in polio free and at-risk countries. Every year delayed eradicating this disease will require $800 million to continue this fight.

Since 1988, tens of thousands of public health workers have been trained to manage massive immunization programs and investigate cases of acute flaccid paralysis. Cold chain, transport and communications systems for immunization have been strengthened. The global network of 145 laboratories and trained personnel established by the GPEI also tracks measles, rubella, yellow fever, meningitis, and other infectious diseases and will do so beyond polio eradication.

A study published in the November 2010 issue of the journal *Vaccine* estimates that the GPEI could provide net benefits of at least $40-50 billion over the next 20 years. As many as 200,000 children could be paralyzed annually in the next 10 years if we do eradicate polio now. Success will ensure that the significant investment made by the US, Rotary International, and many other countries and entities, is protected in perpetuity.

AMERICAN SOCIETY OF NEPHROLOGY

WRITTEN TESTIMONY ON FISCAL YEAR 2017 FUNDING FOR THE NATIONAL INSTITUTE OF DIABETES AND DIGESTIVE AND KIDNEY DISEASES AT THE NATIONAL INSTITUTES OF HEALTH

PREPARED FOR THE LABOR, HEALTH AND HUMAN SERVICES, EDUCATION, AND RELATED AGENCIES SUBCOMMITTEE OF THE UNITED STATES HOUSE OF REPRESENTATIVES COMMITTEE ON APPROPRIATIONS

April 15, 2016

On behalf of the more than 20 million children, adolescents, and adults living with kidney diseases in the United States, the American Society of Nephrology requests $2.165 billion for the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) at the National Institutes of Health (NIH) for Fiscal Year 2017. The society also requests an additional $150 million per year over 10 years for NIDDK-funded kidney research above the current funding level. These are crucial and necessary investments for preventing illness and maintaining fiscal responsibility. Investing in research to slow the progression of kidney diseases and improve therapies for patients would yield significant savings to Medicare in the long run.

Once kidney disease progresses to end-stage renal disease (ESRD), patients need either costly dialysis treatments or a kidney transplant. Because there are not enough kidney donations for every patient who needs one, most of the 662,000 Americans with ESRD are on dialysis at an annual cost of $85,000 per patient. In 1972, Congress

made a commitment to provide Medicare coverage for every American with ESRD so all Americans who needed dialysis would have access to it.

Consequently, ESRD is the only health condition Medicare automatically provides coverage for regardless of age and income. At an annual cost of $35 billion—more than NIH's entire budget of $32 billion—the Medicare ESRD Program represents 7 percent of Medicare's budget even though ESRD patients represent less than 1 percent of the Medicare population. Despite the burden of kidney disease, NIH investments in kidney research are less than 1 percent of total Medicare costs for patients with kidney diseases (approximately $591 million vs. $98.9 billion in 2013).

The vast majority of federal research leading to advances in the care and treatment of Americans with kidney diseases is funded by NIDDK, and there have been several major breakthroughs in the past several years thanks to NIDDK-funded research.

For example, geneticists focused on the kidney have made advances in understanding the biological processes leading to the development of some common kidney diseases. In addition, scientists have announced a method for growing new kidneys in a laboratory, as well as a rapid method for screening new prescription medications using kidney cells that would spare the expense and time of conducting human clinical trials. NIDDK-funded research also led to the development of bioengineered kidneys that are currently undergoing clinical testing.

Change is on the way because of advances made through NIDDK-funded kidney research. Additional, sustained funding is needed to accelerate these and other novel therapies that could improve the care of patients with kidney diseases and result in significant savings to Medicare. A failure to maintain and strengthen NIDDK's ability to support the groundbreaking work of researchers across the country carries a palpable human toll, denying hope to the millions of patients awaiting the possibility of a healthier tomorrow.

The American Society of Nephrology urges Congress to uphold its longstanding legacy of bipartisan support for biomedical research. Should you have any questions or wish to discuss NIDDK kidney research in more detail, please contact Grant Olan, Senior Policy and Government Affairs Associate of the American Society of Nephrology, at (202) 640-4657 or golan@asn-online.org.

ABOUT AMERICAN SOCIETY OF NEPHROLOGY

The American Society of Nephrology is a 501(c)(3) non-profit, tax-exempt organization that leads the fight against kidney disease by educating the society's nearly 16,000 nephrologists, scientists, and other healthcare professionals, advancing research and innovation, communicating new knowledge, and advocating for the highest quality care for patients. For more information, visit www.asn-online.org.

Outside Witness Testimony prepared for
House Committee on Appropriations Subcommittee on
Labor, Health and Human Services, Education, and Related Agencies

Addressing National Institutes of Health, the Centers for Disease Control and Prevention, Department of Health and Human Services, and Assistant Secretary for Health

Charmian Proskauer, Chair
U.S. Action Working Group
April 15, 2016

We request:

- **CDC: Restore funding for ME/CFS in FY17 budget - $6 MM**
- **HHS/Assistant Secretary for Health – Office of Women's Health: Continue funding for Chronic Fatigue Syndrome Advisory Committee - $300,000**
- **NIH: Follow through on recent statements to patients by providing significant and specific funding for ME/CFS research, including RFA's**

I present this testimony on behalf of the members listed below of the U.S. Action Working Group, a coordinating committee for a number of non-profit organizations and patient/advocates working to advance research on the disease **Myalgic Encephalomyelitis/Chronic Fatigue Syndrome** (known as ME/CFS). ME/CFS affects up to 2.5 million people in the U.S., according to the Institute of Medicine, and approximately 17 million more around the world and has been reported in people younger than 10 years of age and the elderly (over 70 years). We represent organizations which provide information on governmental and other programs to patients and advocates; educate government officials, medical professionals, and patients about ME/CFS; and provide direct services to patients.

About ME/CFS

Two major reports, both funded by government agencies, were published in 2015, the NIH's Pathways to Prevention (P2P) report, *"Advancing the Research on Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome,"* and the Institute of Medicine (IOM) report, *"Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Redefining an Illness."*

Myalgic encephalomyelitis/chronic fatigue syndrome, commonly referred to as ME/CFS, is a disease characterized by profound fatigue, cognitive dysfunction, sleep abnormalities, autonomic manifestations, pain, and other symptoms that are made worse by exertion of any sort. ME/CFS can severely impair patients' ability to conduct their normal lives, yet many struggle with symptoms for years before receiving a diagnosis. Fewer than one-third of medical school curricula and less than half of medical textbooks include information about ME/CFS. Although many health care providers are aware of ME/CFS, they may lack essential knowledge about how to diagnose and treat it.

The Institute of Medicine report states:

> "Myalgic encephalomyelitis (ME) and chronic fatigue syndrome (CFS) are serious, debilitating conditions that impose a burden of illness on millions of people in the United States. At least one-quarter of ME/CFS patients are house- or bed-bound at some point in

their lives. The direct and indirect economic costs of ME/CFS to society have been estimated at $17 to $24 billion annually…High medical costs combined with reduced earning capacity often have devastating effects on patients' financial status." (IOM, pp. 1-2)

"Patients with ME/CFS have been found to be more functionally impaired than those with other disabling illness, including type 2 diabetes mellitus, congestive heart failure, hypertension, depression, multiple sclerosis, and end-stage renal disease." (IOM, p. 31)

This devastating disease is not limited to adults. Children and adolescents also get ME/CFS, but there are almost no existing trained medical professionals to give them proper care. One mother writes,

"Both of my children have ME/CFS. As a parent, it has been heartbreaking to watch them suffer from this debilitating illness. My son, now age 20, became sick when he was 12. He missed most of junior and senior high school because he was too sick to physically attend school. My daughter, now age 17, also became sick at the age of 12 and is also too sick to attend school. My children have lost an enormous amount–their health, the social experience of high school, and the ability to participate in things they love like sports and music. It took years of doctor visits and consultations with specialist to receive a diagnosis, and the utter lack of treatments for ME/CFS is incredibly frustrating."

For most of the last 30 years, patients with this disease have received little support from the federal agencies with the most power to help them – NIH and CDC; only very small amounts of funding have been dedicated to researching or finding treatments for the disease or educating the medical community about it. In addition, some of the treatment recommendations provided by the CDC were based on research that is now under review, and have been harmful to patients.

Because of the lack of medical care providers who are properly educated about ME/CFS, and the lack of medical research leading to better understanding of the disease and effective treatments, patients with ME/CFS are often stigmatized or "treated with skepticism, uncertainty, and apprehension" (P2P, p. 4). **As a result, most patients are not able to obtain adequate medical care for their illness, either not getting an accurate diagnosis or receiving inappropriate or no treatment, thereby leaving more than 2 million citizens largely disabled for decades.**

CDC

The patient community was very disturbed to see that the already tiny allocation of $5.4 million for the CDC's ME/CFS program was zeroed out in the President's budget for FY17, a year in which the CDC is scheduled to complete its 4-year multi-site study and begin a new initiative to educate medical professionals about ME/CFS based on the recent findings of Institute of Medicine. The multi-site study will provide a tremendous amount of new information regarding this disease and it is critical that it be completed.

We, therefore, join in asking this Committee to recommend a restoration of the CDC budget for ME/CFS at a level of no less than $6M and urge the CDC to use that to complete its multi-site study, and leverage the recommendations from both the Institute of Medicine and the Chronic Fatigue Advisory Committee to provide to develop and execute a new, broad-based medical education campaign.

To address the lack of access to clinical care, we also ask the Committee to urge the CDC to work with the NIH and other agencies within the Department of Health and Human Services to find creative ways to fund multiple Centers of Excellence (there are none now) and include in them a clinical care component so that patients nationwide might have improved access to expert ME/CFS medical professionals.

NIH

There are NO FDA-approved drugs to treat this disease. In 2014, there were at least 32 FDA-approved drugs to treat HIV/AIDS and nine for Multiple Sclerosis. Why is this? **Because essentially no research dollars are going toward finding new treatments, new drugs, and other useful symptom-reducing interventions.**

Today, research funding from NIH for ME/CFS is far below funding for similarly disabling illnesses with similar or lower prevalence:

- ME/CFS (2 million patients): **Only $3 per patient in NIH funding** - $6 million in 2015
- Multiple sclerosis (400,000 patients): About $235 per patient; $94 million 2015
- HIV/AIDS (1.2 million patients): About $2500 per patient ($3 billion in 2015)

ME/CFS patients are cautiously hopeful to see the recent focus on this disease at the National Institutes of Health, with support from Dr. Francis Collins, Director, and Dr. Walter Koroshetz, Director of the National Institute of Neurological Diseases and Stroke. A Trans-NIH Working Group has been established for this disease, and NIH has also begun planning for an intramural study to begin in the summer of 2016. We recognize the intention of the NIH to expand the extramural research program and applaud the goal of bringing new researchers into the field. However, this will not happen without **funding allocated specifically to this disease.**

We join in asking this Committee to recommend that the NIH make funding for ME/CFS research commensurate with disease burden. This funding is necessary to jump-start the field through a set of intramural and extramural investments that include Requests for Applications (RFAs) for biomarkers and treatment trials, set-aside funding for investigator initiated studies (including for hypothesis generation), regional Centers of Excellence, and support for a network of researchers to develop a research strategy with defined milestones and to reach consensus on a research case definition and research standards.

We further ask that NIH act aggressively to implement these required actions and to collaborate with disease researchers, clinicians, and patients and their advocates in doing so with full transparency for best results.

Department of Health and Human Services (HHS) and Assistant Secretary for Health

The Chronic Fatigue Syndrome Advisory Committee is a Federal Advisory Committee with 11 members of the public, including one patient representative, and non-voting representatives from 7 agencies within HHS. In addition there are up to 3 non-voting "liaison members" from ME/CFS patient or research organizations. It is an important vehicle by which patients can communicate face-to-face and engage in discussions with the agencies. Its charter must be renewed every two years, or it will cease to exist.

We join in asking this Committee to urge HHS and the Assistant Secretary for Health to

continue support of the Chronic Fatigue Syndrome Advisory Committee (CFSAC) with a budget of $300,000 including direct expenses and staff support, to renew its charter in September, 2016, and to accelerate progress on CFSAC's recommendations to strengthen research, education, training, care, and services to better address the needs of two million Americans living with ME/CFS. Further, to address the gaps in medical care highlighted by the recent Institute of Medicine Report, we ask the Committee to urge HHS to find creative ways to fund regional Centers of Excellence that include both a research component and direct clinical care component.

We close with Cheryl's story.

"CFS is an invisible disability. When you look at me, you won't see my broken aerobic metabolism that has cost me my muscle strength, flexibility and endurance. You won't see that taking a shower or preparing a simple meal causes me to exceed my anaerobic threshold, creating lactic acid build-up, exhaustion and pain. You won't see how my sleep is disrupted every night, restless and unrefreshing. You won't see the chronic and debilitating muscle and joint pain, headaches, sore throat, or the intolerance to noise, bright lights, chemicals and foods that were easily tolerated before CFS. You won't see my lost sense of productivity, accomplishment and contribution that I got from career that I loved and was so much of my identity. Or my lost sense of connection with others because socializing exceeds my energy limits. Or that I can no longer be counted on to help family or friends in need, or be an equal partner and companion to my husband. You can't see my uncertainty about the future. You can't see my heart yearning to live fully, while my body and brain deteriorate. But it's real, and it's my CFS story."

On behalf of Cheryl and all other ME/CFS patients, we urge this Committee to take the actions we have outlined above. Thank you.

Members of the U.S. Action Working Group

Massachusetts CFIDS/ME & FM Association
New Jersey ME/CFS Association, Inc.
Solve ME/CFS Initiative
Adriane Tillman, California
Claudia Goodell, Race to Solve ME/CFS, New Mexico
Denise Lopez-Majano, Speak Up About ME, Pennsylvania
Erica Verrillo, Executive Director, American Myalgic Encephalomyelitis and Chronic Fatigue Syndrome Society, Massachusetts
Gail Cooper, JD, California
Jean Harrison, Mothers Against ME, Massachusetts
Lily Chu, MD, MSHS, California
Lori Chapo-Kroger, RN, Pandora Org, Michigan
Margaret Lauritson-Lada, Cambridge, Massachusetts
Mary Dimmock, Connecticut
Meghan-Morgan Shannon MS, Medical Professional with ME and CFSIDS, Pennsylvania
Nansy Mathews, Maryland
Robert and Courtney Miller, 30-year patient and advocate, Reno, Nevada
Sonya Heller Irey, MPIA, Patient-Advocate, Arizona
Terri L. Wilder, ME Advocate/Person living with ME, New York

TESTIMONY OF
HAROLD BROOKS, SENIOR VICE PRESIDENT
OF INTERNATIONAL OPERATIONS
THE AMERICAN NATIONAL RED CROSS

AND ON BEHALF OF
KATHY CALVIN, PRESIDENT
UNITED NATIONS FOUNDATION

IN SUPPORT OF FUNDING FOR THE CENTERS FOR DISEASE CONTROL AND PREVENTION (CDC)

APPROPRIATIONS SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES, EDUCATION AND RELATED AGENCIES

UNITED STATES HOUSE OF REPRESENTATIVES
April 15, 2016

Chairman Tom Cole, Ranking Member Rosa DeLauro, and Members of the Subcommittee, the American Red Cross and the United Nations Foundation appreciate the opportunity to submit testimony in support of measles control activities of the U.S. Centers for Disease Control and Prevention (CDC). The American Red Cross and the United Nations Foundation recognize the leadership that Congress has shown in funding CDC for these essential activities. For FY17, we request that this subcommittee support CDC's global measles control activities at $50 million.

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 impressive results by supporting the vaccination of more than 2 billion children since 2001. In part due to the Measles & Rubella Initiative, global measles mortality dropped 79%, from an estimated 548,000 deaths in 2000 to 114,900 in 2014 (the latest year for which data is available). During this same period, measles deaths in Africa fell by 88%. However, about 315 children still die from measles each day from a virus that can be countered with a safe, effective and inexpensive vaccine. Measles is among the most contagious diseases ever known, and a top killer of children in low-income countries where children have little or no access to medical treatment and are often malnourished. Measles spreads much more easily than the flu or the Ebola virus. In fact, one person infected with measles can infect up to 18 others if s/he has not been vaccinated. In addition, each year more than 100,000 children are born with congenital rubella syndrome (CRS). CRS can cause severe birth defects, including blindness, deafness, heart defects and mental retardation. CRS treatment 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 $1.3 billion and provided technical support in more than 88 developing countries on vaccination campaigns, surveillance and improving routine immunization services. From 2000 to 2014, an estimated 17.1 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.

The majority of measles vaccination campaigns have been able to reach more than 90% of their target populations. Countries recognize the opportunity that measles vaccination campaigns provide in 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 including vitamin A which is crucial for preventing blindness in under nourished children, de-worming medicine to reduce malnutrition, and screening for malnutrition. Doses of oral polio vaccines are also frequently distributed during measles campaigns in polio endemic and high-risk countries. The delivery of polio vaccines in conjunction with measles vaccines in these campaigns strengthens the reach of elimination and eradication efforts of these diseases. The delivery of multiple child health interventions during a single campaign is far less expensive than delivering the interventions separately, and this strategy increases the potential positive impact on children's health from a single campaign.

The extraordinary reduction in global measles deaths greatly contributed to reducing under-five child mortality. However, large outbreaks in several African, European and Asian countries from 2011 to 2014 compromised 2015 measles elimination goals of 90% national coverage rates and 95% reduction in mortality, resulting in a plateau in progress towards measles elimination due in large part to decreased funding support from donors and host governments. These outbreaks highlight the fragility of the last decade of progress. If mass immunization campaigns are not continued with robust funding and support, measles deaths will rapidly increase.

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 that - across the board - prevention of diseases results in an average return on investment, with $58 saved in future costs for every $1 spent.

To achieve 2020 elimination goals and avoid a resurgence of measles, the following actions are required:

- Sustaining the gains in reduced measles deaths, especially in Africa, by strengthening immunization programs to ensure that more than 90% of infants are vaccinated against measles through routine health services as well as conducting timely, high quality mass immunization campaigns. Routine immunization is the foundation to achieving and sustaining high levels of immunity to measles in the community.
- Accelerating the introduction of a second dose of measles containing vaccine into the routine immunization program of eligible countries with support from Gavi, the Vaccine Alliance.
- Fully implementing activities, both campaigns and strengthening routine measles vaccination coverage, in Democratic Republic of Congo, Ethiopia, India, Indonesia, Nigeria, and Pakistan which together account for the majority of measles cases and 65% of measles deaths.
- Securing sufficient funding for measles and rubella-control activities both globally and nationally. This year the Measles & Rubella Initiative faces a funding shortfall of an estimated US $73 million. Implementation of timely measles campaigns is increasingly dependent upon countries funding these activities locally. The decrease in donor funds available at a global level to support measles 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%.

If these challenges are not addressed, the remarkable gains made since 2000 will be lost and a major resurgence in measles deaths will occur.

By controlling measles and rubella cases in other countries, U.S. adults and children are also being protected from the diseases. Measles can cause severe complications such as pneumonia, encephalitis, and even death. A resurgence of measles occurred in the United States between 1989 and 1991, with more than 55,000 cases reported. This resurgence was particularly severe, accounting for more than 11,000 hospitalizations and 123 deaths.

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. The occurrence of measles cases in a country is a reliable indication that a country's routine immunization system is not 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.

In the United States, measles control measures have been strengthened, and endemic transmission of measles cases have been eliminated since 2000 and rubella in 2002. However, importations of measles cases into this country continue to occur each year. Since 2000, the annual number of people reported to have measles ranged from a low of 37 in 2004 to a high of 667 people across 27 states in 2014; the greatest number of cases reported in the U.S. since measles was declared eliminated in 2000. Additionally, on July 2, 2015, Washington State Department of Health confirmed a measles-related death. The human and financial impact of

measles cases, deaths, and outbreaks are substantial, both in terms of the costs to public health departments to conduct contact tracing and in terms of productivity losses among people with measles and parents of sick children. Studies show that a single case of measles in the United States can cost between $100,000 and $200,000 in government expenditures to control.

The Role of CDC in Global Measles Mortality Reduction

Since FY 2001 and until 2015, Congress has provided funding for the purchase of measles vaccine for use in large-scale measles vaccination campaigns in more than 88 countries in Africa and Asia, and for the provision of technical support to Ministries of Health. Specifically, this technical support includes:

- Planning, monitoring, and evaluating large-scale measles vaccination campaigns;
- Conducting epidemiological investigations and laboratory surveillance of measles outbreaks; and
- Conducting operations research to guide cost-effective and high quality measles control programs.

In addition, CDC epidemiologists and public health specialists have worked closely with WHO, UNICEF, the United Nations Foundation, and the American Red Cross to strengthen measles control programs at global and regional levels, and will continue to work with these and other partners in implementing and strengthening rubella control programs. While it is not possible to precisely quantify the impact of CDC's financial and technical support to the Measles & Rubella Initiative, there is no doubt that CDC's support – made possible by the funding appropriated by Congress – was essential in helping achieve the sharp reduction in measles deaths in just thirteen years.

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

In FY 2015, Congress appropriated $49.8 million to fund CDC global measles control activities, and $50 million in FY 2016 for such activities. In FY 2017, the American Red Cross and the United Nations Foundation request sustained funding at the level approved by this committee last year for CDC's measles and rubella control activities to protect the investment of the last decade, prevent measles cases and deaths in the United States. We hope this committee will also look at how we can address the shortfall in funding within the Measles and Rubella Initiative in future years.

Your commitment has brought us unprecedented victories in reducing measles mortality around the world. In addition, your continued support for this initiative helps prevent children from suffering from this preventable disease both abroad and in the United States.

Thank you for the opportunity to submit testimony.

COUNCIL OF ACADEMIC FAMILY MEDICINE

Association of Departments of Family Medicine
Association of Family Medicine Residency Directors
North American Primary Care Research Group
Society of Teachers of Family Medicine

Todd Shaffer, MD
Chair, Council of Academic Family Medicine

Submitted for the Record to the House Appropriations Subcommittee on Labor, HHS, Education, and Related Agencies – April 15, 2016

FY 2017 FUNDING REQUESTS

The member organizations of the Council of Academic Family Medicine (CAFM) are pleased to submit testimony on behalf of programs under the jurisdiction of the Health Resources and Services Administration (HRSA) and the Agency for Healthcare Research and Quality (AHRQ). The CAFM collectively includes family medicine medical school and residency faculty, community preceptors, residency program directors, medical school department chairs, research scientists, and others involved in family medicine education. **We urge the Committee to appropriate at least $59 million for the health professions program, Primary Care Training and Enhancement, authorized under Title VII, Section 747 of the Public Health Service Act under the jurisdiction of the Health Resources and Services Administration (HRSA.) In addition, we recommend the Committee fund the Agency for Healthcare Research and Quality (AHRQ) at no less than $364 million in base discretionary funding to support research vital to primary care.**

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, noted the authors of a recent article in Annals of Family Medicine (Petterson, et al Mar/Apr 2015) The programs we support in our testimony will help build upon our nation's workforce and health infrastructure. They improve primary care services that will produce better health outcomes and help reduce the ever rising costs of health care. In this difficult fiscal climate, we hope the Committee will recognize that the production of a robust primary care workforce is a necessary investment that will ultimately produce long term savings.

Primary Care Training and Enhancement

The Primary Care Training and Enhancement Program (Title VII, Section 747 of the Public Health Service Act) has a long history of providing indispensible funding for the training of primary care physicians. With each successive reauthorization, Congress has modified the Title VII health professions programs to address relevant and timely workforce needs. The most recent authorization directs HRSA to prioritize training in the new competencies relevant to providing care in the patient-centered medical home model. It also calls for the development of infrastructure within primary care departments for the improvement of clinical care and

research, as well as innovations in team management of chronic disease, integrated models of care, and transitioning between health care settings.

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. Passage of the Medicare Access and Chip Reauthorization Act (MACRA), which changes Medicare payment methodologies to incentivize alternatives to traditional fee for service, increases the need for adequate Section 747 funding.

Some areas in need of support for future training include: training in clinical environments that are transforming to 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 interprofessional teams that include diverse professions; and development and implementation of curricula to develop leaders and teachers in practice transformation. Moreover, new competencies will be 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."[i] In order to address some of these challenges, the Advisory Committee recommends that Congress increase funding levels for training under the primary care training health professions program, both in FY2017 and for the next 5 years. The current funding of $38.9 million does not allow for the pent up demand caused by reduced and stagnant funding levels. Only 35 schools or institutions were able to obtain grant funding in the FY15 cycle; we expect approximately another 37 awards to be made in FY2016, but then no new awards in FY2017, unless there is an infusion of approximately $20 million to allow for a new competitive cycle. Family medicine alone has over 100 departments in medical schools and over 450 residencies.

Another study in the Annals of Family Medicine (Phillips and Turner, March/April 2012) stated that "Meeting this increased demand [for primary care physician production] requires a major investment in primary care training." The study continues, "Expansion of Title VII, Section 747 with the goal of improving access to primary care would be an important part of a needed, broader effort to counter the decline of primary care. Failure to launch such a national primary care workforce revitalization program will put the health and economic viability of our nation at risk." Recent evidence of the accuracy of that concern can be found in a report just released last month by the National Association of Community Health Centers. It showed serious staffing vacancies, with the most common vacant clinical position that of family physician. "More than two-thirds (69%) of health centers indicate that they are currently recruiting for at least one family physician."

Primary care health professions training grants under Title VII is 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 support for this program and an increase in funding to $59 million in FY2017 to allow for a robust competitive funding cycle. The following information contains real world examples of Title VII at work in several of your districts.

KANSAS: The University of Kansas in Wichita used two Title VII grants to improve research and scholarly activities in residency programs and to improve Patient Centered Medical Home (PCMH) training through curriculum changes and junior faculty mentoring. The faculty development grant greatly improved scholarly production, research and teaching and long-term retention.

KANSAS: The University of Kansas in Kansas City utilized Title VII grant funding to develop a student clinic working with core faculty on an interprofessional basis where faculty from all disciplines see patients together. The clinic includes a population health experience where students work together to address a specific population health issue in the community.

ALABAMA: The University of South Alabama used Title VII funding to lead in curricular innovation being the first to incorporate multimedia education, standardized patients, point of care evidence-based teaching and patient-based evaluation of medical students. This resulted in a new primary care patient curriculum for first and second year medical students.

OHIO: Using three Title VII grants, the Ohio State Department of Family Medicine developed an educational electronic medical record and virtual patient technology for use in the PCMH, trained medical residents on PCMH modalities such as model ambulatory care training sites, and worked with partners to establish an accountable care organization with a significant primary care focus .

Agency for Health Care Research and Quality (AHRQ)

We are grateful that Congress included budget authority for AHRQ in the FY16 omnibus funding bill. This strengthens the viability of an agency that supports primary care research around the country. The majority of research funding in the United States supports research of one specific disease, organ system, cellular, or chemical process – not for primary care despite the fact that the overall health of a population is directly linked to the strength of its primary health care system. Primary care research includes: translating science into caring for patients,, better organizing health care to meet patient and population needs, evaluating innovations to provide the best health care to patients, and engaging patients, communities, and practices to improve health. AHRQ is uniquely positioned to support best practice research and to help disseminate the research nationwide.

There are six areas that AHRQ highlights that are not available elsewhere in the biomedical research infrastructure: primary care research through Practice-based Research Networks

(PBRNs), practice transformation, patient quality and safety in non-hospital settings, multi-morbidity research, mental and behavioral health provision in communities and primary care practices, and training future primary care investigators. Primary care research needs more adequately trained researchers and AHRQ deliberately promotes this training. Below are some examples of successful AHRQ work that supports primary care practice and patient safety:

OKLAHOMA: The University of Oklahoma, College of Medicine, in Oklahoma City, created the Oklahoma Primary Healthcare Improvement Center to serve as a resource to the emerging Oklahoma Primary Healthcare Extensions System. Part of the Evidence Now Initiative, this grant will support the dissemination of patient-centered outcomes research findings into practices, support 300 primary care practices in risk management around smoking cessation, blood pressure control, statins, and low-dose aspirin, and evaluate the intervention's impact on practice performance.

VIRGINIA: Similar to Oklahoma, above, as part of the nationwide AHRQ Evidence Now initiative, the Chair of VCU Family Medicine has used a consortium grant to establish the "Heart of Virginia Healthcare" Collaborative. The collaborative is helping 250-300 primary care practices reduce cardiovascular risk among patients and establish team care models. Similar grants are active in five other collaboratives in 10 additional states; they are all led by primary care (general internal medicine or family medicine) and are all working to help small to medium primary care practices do a better job of reducing cardiovascular risk in their patients. In addition to Oklahoma and Virginia, the other collaboratives, with the states they involve are: Northwest (led by Group Health, Seattle) and involving practices in **Washington, Idaho, and Oregon**; Southwest (led by U Colorado DFM) and involving **Colorado and New Mexico**; Midwest (led by Northwestern) and involving **Wisconsin, Illinois, and Indiana**; **North Carolina** (led by UNC); and **New York** (led by NYU). We have recruited 250 practices in Virginia, and the other collaboratives have a similar recruitment goal.

TEXAS: At the University of Texas Medical Branch in Galveston, an AHRQ funded project is building patient centered mixed method research skills with a patient-centeredness focus.

UTAH: At the University of Utah in Salt Lake City, a recent AHRQ grant funded one of the few studies on the actual cost of Patient Centered Medical Home services. The work received a significant amount of attention in the literature.

ARKANSAS: The University of Arkansas Medical School (UAMS) in Little Rock used a five year AHRQ grant to increase their medical student family medicine match by 67% over three years. The federal increase relied heavily on the Arkansas growth. Grant strategies included program development, increasing program visibility, and support for interested students.

AHRQ's funds research into multiple chronic conditions – a hallmark of primary care practice. These grants are directed to 1) provide clinicians with tools to develop integrated care plans that reflect patients' conditions, values, preferences, etc., and 2) data to examine the impact of integrated care plans and new care models on utilization and quality of care. Additionally,

funding will be used for data collection to identify how health care teams are organized and if care and outcomes look different in team based practices, compared to traditional practices.

Highlighting the success of AHRQ's patient safety initiatives, a 2014[ii] report showed hospital care to be much safer in 2013 compared to 2010. The report noted a decline of 17% in hospital-acquired conditions, in harm to1.3 million individuals, as well as 50,000 lives saved, and $12 billion in reduced health spending during that period. Research related to the most common acute, chronic, and comorbid conditions that primary care clinicians treat is lacking. AHRQ supports this research that is essential to create a robust primary care system for our nation -- one that delivers higher quality of care and better health while reducing the rising cost of care. Despite this need, little is known about how patients can best decide how and when to seek care, how to introduce and disseminate new discoveries into real life practice, and how to maximize appropriate care.

Unfortunately reduced funding for the agency this year disproportionately impacts AHRQ's efforts to research the care of those with multiple chronic conditions. The agency's research initiative aimed at optimizing care for patients with multiple chronic conditions halted this year due to lack of funds. Restoring AHRQ's funding to FY 2015 levels will support research to provide primary care physicians the tools they need for evidence-based practice.

Sufficient funding for AHRQ can help researchers address these problems confronting our health system today. We recommend the Committee fund AHRQ at a base, discretionary level of at least $364 million for Fiscal Year 2017.

---

[i] http://www.hrsa.gov/advisorycommittees/bhpradvisory/actpcmd/Reports/eleventhreport.pdf
[ii] Publication # 15-0011-EF

APIC Contact:
Lisa Tomlinson
Vice President,
Government Affairs and Practice Guidance
1275 K Street NW, Suite 1000
Washington, DC 20005
(202) 454-2606
ltomlinson@apic.org

SHEA Contact:
Lynne Jones Batshon
Director,
Policy and Practice
1300 Wilson Boulevard, Suite 300
Arlington, VA 22209
(703) 684-0761
lbatshon@shea-online.org

Testimony of The Society for Healthcare Epidemiology of America (SHEA)

and the Association for Professionals in Infection Control and Epidemiology (APIC)

to the U.S. House of Representatives Appropriations Subcommittee on

Labor, Health and Human Services, Education and Related Agencies on

Fiscal Year 2017 Appropriations for the U.S. Department of Health and Human Services (HHS)

April 15, 2016

The Society for Healthcare Epidemiology of America (SHEA) and the Association for Professionals in Infection Control and Epidemiology (APIC) thank you for this opportunity to submit testimony on federal efforts to detect dangerous infectious diseases, protect the American public from preventable healthcare-associated infections (HAIs) and address the rapidly growing threat of antibiotic resistance (AR). We ask that you support the following programs within the **Centers for Disease Control and Prevention (CDC) National Center for Emerging and Zoonotic Infectious Diseases: $427.9 million for Core Infectious Diseases including $200 million for the National Strategy and Action Plan for Combatting Antibiotic Resistant Bacteria (CARB), $21 million for the National Healthcare Safety Network (NHSN), and $30 million for the Advanced Molecular Detection (AMD) Initiative. Additionally, we request $34 million for HAI research activity conducted by the Agency for Healthcare Research and Quality**

(AHRQ) and $4.7 billion for the National Institutes of Health/National Institute of Allergy and Infectious Diseases (NIAID).

According to the CDC, some AR infections are already untreatable. Without immediate intervention, minor infections may become life-threatening and put at risk our ability to perform routine medical procedures or treat diseases. The CDC conservatively estimates that over two million illnesses and about 23,000 deaths are caused by AR infections. In addition, almost 453,000 people each year require hospital care for *Clostridium difficile* (*C. difficile*) infections. In most of these infections, the use of antibiotics was a major contributing factor leading to the illness.

Centers for Disease Control and Prevention (CDC)

SHEA and APIC request $427.9 million for Core Infectious Diseases for FY 2017, which includes funding for the National Strategy and Action Plan for CARB, HAI prevention, AR prevention, and the Emerging Infections Program (EIP). This investment will allow CDC to expand and build upon existing AR and HAI prevention efforts across healthcare settings to reduce the emergence of AR pathogens and improve antibiotic use in the community. CDC will develop evidence-based infection prevention guidelines, work with federal and private sector partners on programming to prevent HAIs and AR, and redesign and expand hand hygiene awareness and educational materials for different healthcare settings.

In FY 2017, CDC will expand the EIP, which helps states, localities and territories protect the public from known infectious disease threats in their communities, maintain our nation's capacity to identify new threats as they emerge, and identify and evaluate prevention strategies. CDC will strengthen the EIP program's infrastructure in the states

and with their partners to ensure successful coordination and implementation of tracking and studies. CDC will also expand the scope of AR activities in current EIP sites and potentially add 1-2 additional EIP sites to the network.

We urge you to support $200 million for the National Strategy and Action plan for CARB, currently in year two of implementation. CDC's funding request will allow full implementation of the Tracking, prevention, and stewardship activities to reach the goals and prevention targets outlined in the CARB National Strategy. The FY 2017 increase will expand the enacted FY 2016 HAI/AR prevention efforts as part of the CARB initiative from 25 states to up to 50 states, six large cities, and Puerto Rico, investing in direct action to implement proven interventions that reduce emergence and spread of AR pathogens and improve appropriate antibiotic use. The CDC will award the majority of the FY 2017 funding increase to states to effectively address the AR threats facing our country. It will also expand the National Healthcare Safety Network (NHSN) Antibiotic Use and Resistance (AUR) reporting option from 130 facilities in 30 states to more than 750 facilities in all 50 states, the Department of Defense, and the Department of Veterans Affairs. This investment will support better understanding and prevention of the spread of potentially preventable and untreatable infections in these settings.

We urge you to support $21 million for CDC's National Healthcare Safety Network (NHSN). The CDC estimates that HAIs cost the healthcare system up to $45 billion annually; at any given time, one in 25 hospitalized patients has a HAI. The CDC provides national leadership and expertise in HAI prevention and protects patients across the healthcare continuum through outbreak detection and control. These activities complement and are informed by the NHSN. This request represents level funding with

the FY 2016 enacted level for the NHSN to support HAI prevention and reporting efforts, and will support in FY 2017 reporting on AR infections in up to 20,000 healthcare facilities across the continuum of care. This investment will target prevention efforts and support assessment of antibiotic prescribing for healthcare facilities, and support of the National Action Plan for CARB. These funds will also enable CDC to continue to provide data for national HAI elimination, guide prevention to targeted healthcare facilities to enhance prevention efforts, and decrease HAI rates. This support will also provide NHSN infrastructure and critical user support and provide innovative HAI prevention approaches. In support of the HHS National Action Plan to Prevent HAIs, CDC will continue to track Central Line-Associated Infections (CLABSI), Catheter Associated Urinary Tract Infections (CAUTI), Surgical Site Infections (SSI), methicillin-resistant *Staphylococcus aureus* (MRSA), and *C. difficile* infections through NHSN reporting in more than 6,000 hospitals, and bloodstream infection reporting in more than 7,000 dialysis facilities.

We urge your continued support of the President's $30 million request 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. CDC needs continued resources to support improvements realized to date, and to succeed in the long run beyond its initial success.

Agency for Healthcare Research and Quality (AHRQ)

We request your support of the proposed investment of $34 million for AHRQ's HAI research activity. The HAI support incudes a total of $11 million for three projects using

the Comprehensive Unit-based Safety Program (CUSP): CAUTI and CLABSI in Intensive Care Units (ICUs); Antibiotic Stewardship in Ambulatory and Long-Term Care Settings and Hospitals; and Enhanced Recovery Protocol for Surgery. The CUSP for Antibiotic Stewardship project is designed to support the National Action Plan for CARB and will extend the use of CUSP to promote the implementation of antibiotic stewardship programs, which seek to reduce inappropriate antibiotic use in ambulatory and long-term care settings as well as hospitals.

National Institutes of Health (NIH)/National Institute of Allergy and Infectious Diseases (NIAID)

SHEA and APIC support the $4.7 billion requested for the National Institutes of Allergy and Infectious Diseases (NIAID) within NIH. NIAID plays a key role in advancing the goals of the National Action Plan for CARB through research to understand how microbes develop resistance and studies to identify novel ways to combat them; translation of laboratory findings into potential treatments, vaccines, and new diagnostic tests, clinical validation of diagnostic tests, and clinical trials to evaluate vaccines and new and existing therapies against drug-resistant microbes.

We thank you for the opportunity to submit testimony and greatly appreciate your leadership in the effort to eliminate preventable HAIs, combat antibiotic resistance and improve patient safety and outcomes.

About 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 antimicrobial 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.

About APIC: APIC's mission is dedicated to creating a safer world through prevention of infection. The association's more than 15,000 members direct and maintain infection prevention programs that prevent suffering, save lives and contribute to cost savings for hospitals and other healthcare facilities.

neuac
National Energy and Utility Affordability Coalition

U.S. House of Representatives Committee on Appropriations
Subcommittee on Labor, Health and Human Services, Education and Related Agencies

Written Testimony of Mary Thompson Grassi, Interim Executive Director,
The National Energy and Utility Affordability Coalition (NEUAC)

In support of no less than $4.7 billion in FY17 funding for the Low Income Home Energy Assistance Program (LIHEAP) (Agency: HHS/ACF/OCS)

The Low Income Home Energy Assistance Program (LIHEAP) is America's cornerstone energy safety net program. Since its inception nearly 35 years ago, LIHEAP has assisted low-income families, those on a fixed income and seniors, to ease energy burdens, especially in the cold winter and hot summer months. LIHEAP is federally administered by the U.S. Department of Health and Human Services, Administration of Children and Families, Office of Community Services. It is presently funded at $3.39 billion. The President's FY17 budget proposes a cut of $390 million to LIHEAP's discretionary appropriation. The National Energy and Utility Affordability Coalition (NEUAC) urges you to reject that proposed cut and instead restore LIHEAP funding to earlier levels of at least $4.7 billion for FY17.

Why the need for more funding? In FY15 LIHEAP served about 18 percent of qualifying U.S. households. In other words, 82 percent of LIHEAP-eligible households received no assistance. (National and state by state fact sheets about LIHEAP can be found at http://neuac.org/wp-content/uploads/2015/10/2016LADStateSheetsFINAL.pdf.)

Federal eligibility rules governing LIHEAP require that household income may not exceed 150 percent of the federal poverty level or 60 percent of the state's median income. Simply stated, a family of three would only qualify if they made less than $30,000 annually. However, most LIHEAP recipients fall well under that requirement; according to HHS the typical family receiving assistance in FY14 had a median income of 83.5 percent of the federal poverty guidelines – about $16,000.[1]

Families who rely on LIHEAP are truly the most vulnerable among us. State LIHEAP administrators report that nearly 73 percent of LIHEAP recipient households had at least one vulnerable person, that is a senior age 60 or older, a child age 5 and under, or an individual with a disability.[2]

[1] HHS FY2017 Budget Justification; https://www.acf.hhs.gov/sites/default/files/olab/final_cj_2017_print.pdf
[2] NEADA 2014 LIHEAP Household Report http://neada.org/wp-content/uploads/2015/06/State-Table-FY14-Households-Served.pdf

LIHEAP is not an entitlement, it must come before Congress every year and no one is assured of assistance, not even households in crisis. Since 2009, LIHEAP funding has been reduced by one third, but the need has not fallen by a similar measure.

NEUAC notes that while the Administration seeks a cut in the discretionary LIHEAP funding in FY17, it did include a *"a contingency fund providing additional mandatory funds to respond to increases in the number of low-income households, spikes in the price of natural gas, electricity, or oil, and extreme cold at the beginning of winter."*

Additionally, the Administration proposes allowing states to *"use up to 40 percent"* of its LIHEAP appropriation for weatherization *"without regard to the waiver process."* Currently, a state is not required to spend any LIHEAP money on weatherization. Further, states are limited to not more than 15 percent to be used for weatherization without a waiver, and with a waiver, states may spend a maximum of 25 percent on weatherization. There is already a federal block grant for low-income weatherization, funded in the Energy and Water Development Appropriations bill.

NEUAC's position is that while both proposals are well-intentioned; they have the practical effect of reducing the commitment of core LIHEAP resources to states and tribes. Thus, NEUAC opposes both proposals, and urges the Subcommittee to maximize its commitment to LIHEAP, to concentrate all resources into the program's base block grants, and to enable the program to focus upon the core mission Congress established it to accomplish.

Thank you for the opportunity to express the views of the National Energy and Utility Affordability Coalition on this important matter. We thank you for consideration of our request to fund LIHEAP at an amount no lower than $4.7 billion in FY17.

###

NEUAC is national, broad-based and diverse. Its mission is to heighten awareness of the energy needs of low- and moderate-income Americans. NEUAC members – including non-profits, fuel funds, energy providers, charitable organizations, tribes, and many others – are working to reduce the energy burden of vulnerable households through advocacy, policy improvements and partnerships.

National Energy and Utility Affordability Coalition
303 East 17th Avenue, Suite 350, Denver, CO 80203
720-402-3125 | email: mgrassi@neuac.org
http://www.neuac.org/

STAVROS

CENTER FOR INDEPENDENT LIVING, INC.

Dear the House LHHS Appropriations Subcommittee:

My name is Jennifer Lee and I am the Systems Advocate for Stavros. I am writing to support the National Council on Independent Living's (NCILs) request for increased funding in the HHS appropriations for Centers for Independent Living (CILs). I am asking that you support a funding increase of $200 million, for a total of $301 million for the Independent Living line item in FY 2017.

Like Stavros, CILs are cross-disability, community-based, nonprofit organizations. CILs are governed and staffed by people with all types of disabilities. Each of the centers, provide supports through five core services: information and referral, individual and systems advocacy, peer support, independent living skills training, and transitional services. From 2012-2014, CILs collectively provided these core services to nearly 5 million people with disabilities. Beyond these core services, centers provide additional services such as housing assistance, transportation, personal care attendants, and employment services to hundreds of thousands of individuals. Resulting from their combined efforts, CILs have transitioned 13,030 people with disabilities from nursing homes and other institutions into the community. Without the work of Stavros and other CILs many would remain institutionalized and would remain isolated from educational, recreational, and employment opportunities within the community.

In 2014, transition services were added as a fifth core service under the Workforce Innovation and Opportunity Act (WIOA). Transition services consist of the reintegration of people with disabilities back into the community and working to prevent at risk people with disabilities from entering institutionalized settings. Transition service also include supporting transitional aged youth as they transition into adulthood and seek independence. Stavros believes that this fifth core service is vital to achieving full participation for people with disabilities.

Everyday CILs, like Stavros are fighting to ensure that people with disabilities gain and maintain control over their lives. But the supports that CILs offer are costly and require funding in order to sustain them. Funding support is necessary to restore the devastating cuts to the Independent Living program, make up for inflation costs, and address the increased demand for independent living services. In 2016, the Independent Living Program is receiving $2.5 million less in funding than it was allotted in 2010. It is simply not possible to meet the increasing demand for services and effectively provide transition services without additional funding.

All in all, Centers for Independent Living play a crucial role in the lives of people with disabilities, and work tirelessly to ensure that people with disabilities have a real choice in where and how they live, work, and participate in the community. Overall, Stavros strongly supports NCIL's request for a funding increase for the Independent Living line item in FY 2017.

Thank you for your continuous support!

Best,

Jennifer L. Lee
Systems Advocate for Change,
Stavros CIL
413-256-0473

United Way Partner Agency

210 Old Farm Road
Amherst, MA 01002-2704
(800) 804-1899 V/TDD
(413) 256-0473 V/TDD
Fax (413) 256-0190
www.stavros.org

Fiscal Intermediary Office
210 Old Farm Road
PO Box 2130
Amherst, MA 01004-2130
(800) 442-1185 V/TDD
(413) 256-6692 V/TDD
FAX (413) 256-3849

55 Federal Street Suite 201
Greenfield, MA 01301-2543
(413) 774-3001 V/TDD
(413) 772-2556 TDD Only
Fax (413) 772-2556

227 Berkshire Avenue
Springfield, MA 01109-1638
(413) 781-5555 V/TDD
Fax (413) 733-5473

William L. Dewey, Ph.D., President
Friends of the National Institute on Drug Abuse

Mr. Chairman and Members of the Subcommittee, thank you for the opportunity to submit testimony to the Subcommittee in support of the National Institute on Drug Abuse (NIDA). The Friends of the National Institute on Drug Abuse is a coalition of over 150 scientific and professional societies, patient groups, and other organizations committed to preventing and treating substance use disorders as well as understanding their causes through the research agenda of the National Institute on Drug Abuse (NIDA). Recognizing that so many health research issues are inter-related, we request that the subcommittee provide at least $34.5 billion for the National Institutes of Health (NIH) and within that amount a proportionate increase for the National Institute on Drug Abuse, in your Fiscal 2017 Labor, Health and Human Services, Education and Related Agencies Appropriations bill. We also respectfully request the inclusion of the following NIDA specific report language.

Opioid Misuse and Addiction. *The Committee is concerned about the escalating epidemic of prescription opioid and heroin use, addiction and overdose in the U.S. Nearly 130 people die each day in this country from opioid overdose, making it one of the most common causes of death for adolescents and young adults. The Committee appreciates the important role that research can and should play in the various federal initiatives aimed at this crisis. The Committee urges NIDA to 1) continue funding research on medications to alleviate pain, including the development of those with reduced abuse liability; 2) as appropriate, work with private companies to fund innovative research into such medications; and 3) report on what we know regarding the transition from opioid analgesics to heroin abuse and addiction within affected populations.*

Adolescent Brain Development. *The Committee recognizes and supports the Adolescent Brain and Cognitive Development (ABCD) Study. We know that the brain continues to develop into the mid-twenties. However, we do not yet know enough about the dramatic brain development that takes place during adolescence and how the various experiences children are exposed to during this time (e.g., sports injuries, lack of sleep, marijuana or other substance use) interact with each other and a child's biology to affect brain development and, ultimately, social, behavioral, health and other outcomes. As part of the Collaborative Research on Addiction (CRAN), a trans-NIH consortium involving NIDA, NIAAA, and NCI, and in partnership with NICHD, NINDS, NIMH, NIMHD, and OBSSR, the ABCD study intends to address this knowledge gap. As the largest ever longitudinal brain-imaging study of youth, the ABCD study will follow approximately 10,000 U.S. children from ages 9-10 into early adulthood, who will provide behavioral, neuroimaging, genetic, and other health data throughout development. The ABCD study will yield critical insights into the foundational aspects of adolescence that shape life trajectories. The committee also recommends and recognizes that the cost of this comprehensive study should not inhibit investigator initiated studies or any potential special appropriation for its ongoing support.*

Marijuana Research. *The Committee is concerned that marijuana public policies in the states (medical marijuana, recreational use, etc.) are being changed without the benefit of scientific research to help guide those decisions. The Committee is also concerned that restrictions*

associated with Schedule 1 of the Controlled Substance Act effectively limit the amount or type of research that can be conducted on marijuana or its component chemicals. NIDA is encouraged to continue supporting a full range of research on the effects of marijuana and its components, including policy research focused on policy change and implementation across the country. The Committee also directs NIDA to provide a short report on the barriers to research that result from the classification of marijuana as a Schedule 1 substance.

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. Through its NIDAMeD initiative, NIDA is advancing addiction awareness, prevention, and treatment in primary care practices through seven Centers of Excellence for Physician Information. Intended to serve as national models, these centers target physicians-in-training, including medical students and resident physicians in primary care specialties (*e.g., *internal medicine, family practice, and pediatrics). NIDA also developed, in partnership with the Office of National Drug Control Policy, two online continuing medical education courses on safe prescribing for pain and managing patients who abuse prescription opioids. These courses were viewed by over 200,000 individuals and completed for credit by over 100,000 clinicians combined. The Committee continues to be pleased with NIDAMed, and urges the Institute to continue its focus on activities to provide physicians and other medical professionals with the tools and skills needed to incorporate drug abuse screening and treatment into their clinical practices.*

Medications Development. *The Committee recognizes that new technologies are required for the development of next-generation pharmaceuticals. In the context of NIDA funding, chief among these are NIDA's current approaches to develop viable immunotherapeutic or biologic (e.g., bioengineered enzymes) approaches for treating addiction. The goal of this research is the development of safe and effective vaccines or antibodies that target specific addictive drugs, like nicotine, cocaine, and heroin, or drug combinations. The Committee is encouraged by this approach - if successful, immunotherapies, alone or in combination with other medications, behavioral treatments, or enzymatic approaches, stand to revolutionize how we treat, and ultimately prevent addiction.*

Drug Treatment in Justice System Settings. *The Committee understands that providing evidence-based treatment for substance use disorders offers the best alternative for interrupting the drug use/criminal justice cycle for offenders with drug problems. Untreated substance using offenders are more likely to relapse into drug use and criminal behavior, jeopardizing public health and safety and taxing criminal justice system resources. Treatment has consistently been shown to reduce the costs associated with lost productivity, crime, and incarceration caused by drug use. This reality represents a significant opportunity to intervene with a high-risk population. In 2013 NIDA launched the Juvenile Justice Translational Research on Interventions for Adolescents in the Legal System (JJ-TRIALS) program to identify and test strategies for improving the delivery of evidence-based substance abuse and HIV prevention and treatment services for justice-involved youth. The JJ-TRIALS initiative will provide insight into the process by which juvenile justice and other service settings can successfully adopt and adapt existing*

evidence-based programs and strategies to improve treatment for at-risk youth. The Committee supports this important work and asks for a progress report in the next appropriations cycle.

Electronic Cigarettes. *The Committee understands that electronic cigarettes (e-cigarettes) are increasingly popular among adolescents. Lack of regulation, easy availability, and a wide array of cartridge flavors may make them particularly appealing to this age group. In addition to the unknown health effects, early evidence suggests that e-cigarette use may serve as an introductory product for youth who then go on to use other tobacco products, including conventional cigarettes, which are known to cause disease and lead to premature death. Early evidence also reveals that these devices are widely used as tools for smoking derivatives of marijuana (hash oil, "shatter," etc.) The Committee requests that NIDA fund research on the use and consequences of these devices.*

Drug abuse is costly to Americans; it ruins lives, while tearing at the fabric of our society and taking a huge financial toll on our resources. Beyond the unacceptably high rates of morbidity and mortality, drug abuse is often implicated in family disintegration, loss of employment, failure in school, domestic violence, child abuse, and other crimes. Placing dollar figures on the problem; smoking, alcohol and illegal drug use results in an exorbitant economic cost on our nation, estimated at over $600 billion annually. We know that many of these problems can be prevented entirely, and that the longer we can delay initiation of any use, the more successfully we mitigate future morbidity, mortality and economic burdens.

Over the past three decades, NIDA-supported research has revolutionized our understanding of addiction as a chronic, often-relapsing brain disease –this new knowledge has helped to correctly emphasize the fact that drug addiction is a serious public health issue that demands strategic solutions. By supporting research that reveals how drugs affect the brain and behavior and how multiple factors influence drug abuse and its consequences, scholars supported by NIDA continue to advance effective strategies to prevent people from ever using drugs and to treat them when they cannot stop.

NIDA supports a comprehensive research portfolio that spans the continuum of basic neuroscience, behavior and genetics research through medications development and applied health services research and epidemiology. While supporting research on the positive effects of evidence-based prevention and treatment approaches, NIDA also recognizes the need to keep pace with emerging problems. We have seen encouraging trends – significant declines in a wide array of youth drug use -- over the past several years that we think are due, at least in part, to NIDA's public education and awareness efforts. However, areas of significant concern include the recent increase in lethalities due to heroin and synthetic fentanyl, as well as the continued abuse of prescription opioids and the recent increase in availability of designer drugs and their deleterious effects. The need to increase our knowledge about the effects of marijuana is most important now that decisions are being made about its approval for medical use and/or its legalization. We support NIDA in its efforts to find successful approaches to these difficult problems.

The nation's previous investment in scientific research to further understand the effects of abused drugs on the body has increased our ability to prevent and treat addiction. As with other

diseases, much more needs be done to improve prevention and treatment of these dangerous and costly diseases. Our knowledge of how drugs work in the brain, their health consequences, how to treat people already addicted, and what constitutes effective prevention strategies has increased dramatically due to support of this research. However, since the number of individuals continuing to be affected is still rising, we need to continue the work until this disease is both prevented and eliminated from society.

We understand that the FY2017 budget cycle will involve setting priorities and accepting compromise, however, in the current climate we believe a focus on substance abuse and addiction, which according to the World Health Organization account for nearly 20 percent of disabilities among 15-44 year olds, deserves to be prioritized accordingly. We look forward to working with you to make this a reality. Thank you for your support for the National Institute on Drug Abuse.

tulsacares

Testimony Prepared by R. Shannon Hall, Executive Director of Tulsa CARES for the United State House Subcommittee on Labor, Health and Human Services, Education, and Related Agencies addressed to the Department of Health and Human Services

April 15, 2015

We are pleased to submit this testimony to the Members of this Subcommittee on the urgency of continuing to support the Ryan White Program through the Appropriations process and increasing funding for the domestic HIV/AIDS portfolio in Fiscal Year 2017 (FY17). This support and funding will be decisive for achieving the goals of the National HIV/AIDS Strategy (NHAS) 2020, the AIDS Free Generation and halting the devastating effects of the HIV Treatment Cascade.

Tulsa CARES is part of a nationwide coalition, the Food is Medicine Coalition, of food and nutrition services providers, affiliates and their supporters across the country that provide food and nutrition services to people living with HIV/AIDS (PWH) and other chronic illnesses. In our service area, we provide nutrition, farmer's market, and food pantry services to 475 individuals annually. Collectively, the Food is Medicine Coalition is committed to increasing awareness of the essential role that food and nutrition services (FNS) play in successfully treating HIV/AIDS and to expanding access to this indispensable intervention for people living with other severe illnesses.

1.) Why Food and Nutrition Services (FNS) Matter for PWH

While adequate food and nutrition are basic to maintaining health for all persons, good nutrition is crucial for the management of HIV infection. Proper nutrition is needed to increase absorption of medication, reduce side effects, and maintain healthy body weight. Research has identified the virus as an independent risk factor for cardiovascular, liver and kidney disease, cancer, osteoporosis and stroke. Several HIV medications can cause nausea and vomiting and some can affect lab results that test lipids and kidney and liver function. These compounding health effects, caused by the virus and its medications, reinforce the important role a nutrient-rich diet plays in a patient's overall care plan. In addition, providing food and nutrition services can serve to facilitate access and engagement with medical care, especially among vulnerable populations.

The Food and Nutrition Services category within the Ryan White Program includes medical nutritional therapy (MNT) and food and nutrition services (FNS). MNT covers nutritional diagnostic, therapy, and counseling services focused on prevention, delay or management of diseases and conditions, and involves an in-depth assessment, periodic reassessment and intervention provided by a licensed, Registered Dietitian Nutritionist (RDN) outside of a primary care visit. The range of FNS provided through the Ryan White program complements the needs of PWH at any stage of their illness. For those who are most mobile, there are congregate meals, walk-in food pantries and voucher programs. For those whose disease has progressed, home-delivered meals and home-delivered grocery bags complement their medical treatment.

Since 2006, HRSA has included MNT and FNS, provided under the guidance of RDNs, as a clinically effective **core medical service** in the Ryan White Program. These services play a critical role in ensuring that PWH enter and continue in primary medical care, adhere to their medications, and ultimately achieve viral suppression.

2.) FNS as a Care Completion Service Unique to Ryan White

Social and economic interventions, most often in the form of care completion service like food and nutrition services, are fundamental to making health care work for PWH. Support services for PWH are not covered in any comprehensive way by Medicaid or other public insurance initiatives that have been expanded by the Affordable Care Act. As the HIV epidemic in the United States increasingly impacts low-income individuals, support services help stabilize individuals living with or at risk of HIV. When needs are met, and life's emergencies are held at bay, PWH are poised to remain connected to care and treatment.

3.) Access to FNS and the Triple Aim

Access to appropriate food and nutrition services (FNS) are increasingly recognized as key to accomplishing the triple aim of national healthcare reform for PWH.

Better Health Outcomes

When clients get effective FNS and become food secure, they then keep scheduled primary care visits; score higher on health functioning, are at lower risk for inpatient hospital stays and are more likely to take their medicines[i]. Studies show both the health benefits of access to MNT and/or nutrition counseling for people with HIV infections[ii] and the resulting decreases in their healthcare costs. Compare these outcomes to PWH who are food insecure, who have:

- Lower CD4 counts & lower likelihoods of having undetectable viral loads[iii]
- More ER visits[iv] & increased morbidity and mortality[v]
- More missed primary care appointments & reduced use of antiretroviral therapy[vi].

Lower Healthcare Costs

Millions of dollars in healthcare expenditures are saved through the provision of FNS to PWH. A recent study comparing participants in a medically-tailored FNS program vs. a control group within a local managed care organization found that average monthly healthcare costs for PWH fell 80% in first three months after receiving FNS[vii]. If hospitalized, nourished clients' costs were 30% lower, their hospital length of stay was cut by 37% and they were 20% more likely to be able to be discharged to their homes rather than a more expensive institution[viii]. Furthermore, FNS are a very inexpensive intervention. For each day in a hospital saved, you can feed a person a medically-tailored diet for half a year.

Improved Patient Satisfaction

Studies show nutrition counseling improves quality of life[ix]. Members overwhelmingly report that our services help them live more independently, eat more nutritiously and manage their medical treatment more effectively.

4.) FNS and the National HIV/AIDS Strategy (NHAS)

Access to FNS for PWH is fundamental to fulfilling the goals of the NHAS.

- **NHAS Goal: Reducing new HIV infections:** PWH who are food insecure are less likely to have undetectable viral loads in a statistically significant way. Undetectable viral loads prevent transmission 96% of the time[x], thus, FNS is key to prevention[xi].
- **NHAS Goal: Increasing access to care and improving health outcomes for people living with HIV:** PWH who receive effective FNS are more likely to keep scheduled primary care visits, score higher on health functioning, are at lower risk for inpatient hospital stays and are more likely to take their medicines[xii].
- **NHAS Goal: Reducing HIV-related disparities and health inequities:** By providing FNS to PWH who are in need largely because of poverty, we improve health outcomes, thereby reducing health disparities[xiii].
- **NHAS Goal: Achieving a more coordinated national response to the HIV epidemic:** There remains a tremendous variation by state in coverage of food and nutrition services both inside and outside of Ryan White, making support for Ryan White HIV Program all the more needed. Ultimately, if we are going to achieve a more coordinated national response to the HIV epidemic and our quest to reduce healthcare spending nationwide, FNS must be included in all healthcare reform efforts, including Ryan White and the ACA.

Conclusion

We are deeply aware of the difficult decisions that face the members of the Committee in the current fiscal environment. Yet, research shows that investment in FNS, with the great return in prevention and retention in HIV care, are vital to lowering the number of new infections in the domestic HIV epidemic and ultimately reducing healthcare costs and preserving healthcare resources for the future. A client's diet can literally have life and death consequences. When people are severely ill, good nutrition is one of the first things to deteriorate, making recovery and stabilization that much harder, if not impossible. Early and reliable access to medically-appropriate FNS helps PWH live healthy and productive lives, produces better overall health outcomes and reduces health care costs.

Along with our colleagues, we appreciate the opportunity to offer this testimony regarding the FY 2017 Appropriations process. We are also pleased to offer our assistance and expertise, including information from our Research Library.

Thank you.

R. Shannon Hall
Executive Director
Tulsa CARES
3712 East 11th Street
Tulsa, OK
918-834-4194
ShannonH@tulsacares.org

---

[i] Aidala A, Yomogida M, Vardy Y & the Food & Nutrition Study Team. Food and Nutrition Services, HIV Medical Care, and Health Outcomes. New York State Department of Health: Resources for Ending the Epidemic, 2014. Available at

https://www.health.ny.gov/diseases/aids/ending_the_epidemic/docs/key_resources/housing_and_supportive_services/chain_factsheet3.pdf

[ii] Academy of Nutrition and Dietetics (formerly American Dietetic Association). HIV/AIDS Nutrition Evidence Analysis Project at http://www.adaevidencelibrary.com/conclusion.cfm?conclusion_statement_id=250707 Accessed 29 July 2012.

[iii] Aidala A., Yomogida M., and the HIV Food & Nutrition Study Team (2011);
Singe AW,Weiser SD, McCoy, SI. Does Food Insecurity Undermine Adherence to Antiretroviral Therapy? A Systematic Review. AIDS Behav (2015) 19:1510–1526.

[iv] Ibid.

[v] Anema A, Chan K, Yip B, Weiser S, Montaner JSG, Hogg RS. Impact of food insecurity on survival among HIV-positive injection drug users receiving antiretroviral therapy in a Canadian cohort. 141st APHA Annual Meeting, Nov. 2-6, 2013. Boston, MA. Abstract #: 290277

[vi] Aidala A., Yomogida M., and the HIV Food & Nutrition Study Team (2011).

[vii] Gurvey J, Rand K, Daugherty S, Dinger C, Schmeling J, Laverty N. Examining Health Care Costs Among MANNA Clients and a Comparison Group. J Prim Care Community Health. (2013) 4:311-317

[viii]Ibid.

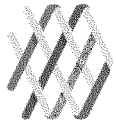
[ix] Rabeneck L, Palmer A, Knowles JB, Seidehamel RJ, Harris CL, Merkel KL, Risser JMH, Akrabawi SS. A randomized controlled trial evaluating nutrition counseling with or without oral supplementation in malnourished HIV-infected patients. J Am Diet Assoc. (1998) 98: 434-438;Schwenk A, Steuck H, Kremer G. Oral supplements as adjunctive treatment to nutritional counseling in malnourished HIV-infected patients: randomized controlled trial. Clinical Nutrition (1999) 18(6): 371-374.

[x] M. S. Cohen *et al.*, Prevention of HIV-1 Infection with Early Antiretroviral Therapy. N. Engl. J. Med.(2011) 365, 493-505 . HPTN 052

[xi] Palar K, Laraia B, Tsai A, Weiser SD Food insecurity is associated with sexually transmitted infections and HIV serostatus among low income adults in the National Health and Nutrition Examination Survey (NHANES) (1999-2010). Presented at the American Public Health Association 141st Annual Meeting, Boston, MA, November 5, 2013.

[xii] Aidala A, Yomogida M, Vardy Y & the Food & Nutrition Study Team. Food and Nutrition Services, HIV Medical Care, and Health Outcomes. New York State Department of Health: Resources for Ending the Epidemic, 2014. Available at

xiii Weiser SD, Frongillo EA, Ragland K, Hogg RS, Riley ED, Bangsberg DR. Food insecurity is associated with incomplete HIV RNA suppression among homeless and marginally housed HIV-infected individuals in San Francisco. J Gen Intern Med. (2009) 24(1):14-20.



American
Alliance of
Museums

Testimony of Laura L. Lott,
President and CEO, American Alliance of Museums,
www.aam-us.org
to the House Appropriations Subcommittee
on Labor, Health and Human Services, Education and Related Agencies
in support of the IMLS Office of Museum Services
April 15, 2016

Chairman Cole, Ranking Member DeLauro, and members of the Subcommittee, thank you for allowing me to submit this testimony on behalf of our members and the nation's larger museum community. My name is Laura L. Lott and I serve as President and CEO of the American Alliance of Museums. I respectfully request that the Subcommittee make a renewed investment in museums in Fiscal Year (FY) 2017. I urge you to fully fund the Office of Museum Services (OMS) at the Institute of Museum and Library Services (IMLS) at its authorized level of $38.6 million.

Before explaining this request, I want to express gratitude for the increase of roughly $1.2 million for OMS that was enacted last year by the Subcommittee in the Consolidated Appropriations Act, Public Law 114-113. Your support for museums will help them make a bigger impact in communities nationwide. I know that the Subcommittee once again likely faces a very limited 302(b) allocation, and must make difficult decisions. In this context, however, I would posit that this extremely 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.

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

Museums are economic engines and job creators: We are proud to report that U.S. museums employ 400,000 people and directly contribute $21 billion to their local economies.

This Subcommittee may be especially interested in the ways museums are providing educational programming and the results of this investment:

- Museums spend more than $2 billion each year on education activities; the typical museum devotes three-quarters of its education budget to K-12 students, and museums receive approximately 55 million visits each year from students in school groups.

- Children who visited a museum during kindergarten had higher achievement scores in reading, mathematics and science in third grade than children who did not. This benefit is also seen in the subgroup of children who are most at risk for deficits and delays in achievement.
- According to a recent study by researchers at the University of Arkansas, students who attended a field trip to an art museum experienced an increase in critical thinking skills, historical empathy and tolerance. For students from rural or high-poverty regions, the increase was even more significant.
- Museums help teach the state and local curriculum, adapting their programs in math, science, art, literacy, language arts, history, civics and government, economics and financial literacy, geography and social studies.
- Many museums are tailoring programs to serve homeschooling families.

IMLS is the primary federal agency that supports the museum field, and OMS awards grants in every state to help museums digitize, enhance and preserve their collections; provide teacher training; and create innovative, cross-cultural and multi-disciplinary programs and exhibits for schools and the public.

In late 2010, legislation to reauthorize IMLS for five years was enacted (by voice vote in the House and by unanimous consent in the Senate). The bipartisan reauthorization included several provisions proposed by the museum field, including enhanced support for conservation and preservation, emergency preparedness and response and statewide capacity building. The reauthorization also specifically supports efforts at the state level to leverage museum resources, including statewide needs assessments and the development of state plans to improve and maximize museum services throughout the state. That bill (Public Law 111-340) authorized $38.6 million for the IMLS Office of Museum Services to meet the growing demand for museum programs and services. The Fiscal Year 2016 appropriation of $31.3 million still falls well below its recent high of $35.2 million in FY 2010.

While the funding increase proposed by the president's budget is extremely small, it reflects some priority areas in which museums could make a greater impact with more federal investment, such as STEM education, national digital infrastructure, and early childhood-family learning. The budget also sets out key strategic focuses on training for collections care, deepening museums' role as community-centered organizations, and serving veterans and military families.

We applaud the 160 bipartisan Representatives who wrote to you in support of FY 2017 OMS funding, including record numbers of Democrats and Republicans, as well as subcommittee members Fattah and Lee.

Here are a few examples, just from 2015, of how IMLS Office of Museum Services funding is used:

Stewardship of Genetics Resources Collection—Sam Noble Oklahoma Museum of Natural History (Norman, OK) was awarded $128,863 to rehouse its collection of genetics resources in a new storage system that will eliminate its dependence on electricity. The museum will broadly disseminate the project results, connecting the collection to research and increasing public awareness about the importance of genetic resources and the museum's role in genetics research. The project will support scholarly research and contribute to the multidisciplinary teaching, research, and outreach missions of the museum and the University of Oklahoma.

Collections Access and Coordination—Tennessee Aquarium (Chattanooga, TN) was awarded $112,078 to partner with Tennessee Technological University to develop the Freshwater Information Network, an interactive portal that combines museum records, recent survey data, and photo archives to provide biologists and resource managers with a platform for connecting and sharing the best scientific information on aquatic animals. This will enhance the conservation value of museum data by better connecting it to researchers, students, resource managers, conservation organizations, and others.

Afterschool Skills Development for High-Needs Districts—Peabody Museum of Natural History (Yale University, New Haven, CT) was awarded $149,364 to add a video production initiative to its free afterschool program, which serves 120 high school students each year from underserved districts. The students will create a series of short films that interpret the work of the museum's researchers and curators. In doing so, they will develop STEM literacy and transferrable skills while increasing dissemination of the museum's work.

Community Anchors—Oakland Museum of California (Oakland, CA) was awarded $149,768 to lead a two-year planning process with the community about its needs and its future, resulting in a comprehensive plan for designing and executing cultural elements in the neighborhood immediately surrounding the museum. The project will benefit the entire Oakland community—residential, business, educational and social—as its members create a shared vision for a vital, creative center for the region.

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

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. Due to the large number of grant applications and the limited funds available, many highly-rated grant proposals go unfunded each year. In 2015:

- Only 39% of Museums for America project proposals were funded;
- Only 30% of National Leadership Grants for Museums project proposals were funded;

- Only 15% of Sparks! Ignition Grants for Museums project proposals were funded;
- Only 66% of Native American/Hawaiian Museum Services project proposals were funded; and
- Only 37% of African American History and Culture project proposals were funded.

Again, I know the subcommittee faces difficult decisions and am grateful for your previous support. If I can provide any additional information about the essential role of the museums in your community, I would be delighted to do so. Thank you once again for the opportunity to submit this testimony today.

Testimony for Submission

Murray Penner
Executive Director
National Alliance of State and Territorial AIDS Directors
mpenner @NASTAD.org – 202.434.8090

To the House Committee on Appropriations
Subcommittee on Labor, HHS, Education and Related Agencies for FY2017

The National Alliance of State & Territorial AIDS Directors (NASTAD) represents the nation's chief state health agency staff who have programmatic responsibility for administering HIV and hepatitis healthcare, prevention, education, and supportive service programs funded by state and federal governments. On behalf of NASTAD, we urge your support for increased funding for federal HIV and hepatitis programs in the FY2017 Labor-Health-Education Appropriations bill, and thank you for your consideration of the following critical funding needs for HIV and hepatitis programs in FY2017:

Agency	**Program**	**NASTAD Funding Request**
Health Resources and Services Administration	Ryan White Part B Base	$437 million
Health Resources and Services Administration	Ryan White Part B ADAP	$943.3 million
Centers for Disease Control and Prevention	Division of HIV Prevention	$822.6 million
Centers for Disease Control and Prevention	Division of Viral Hepatitis	$62.8 million

For the first time, we can visualize the end of the HIV and hepatitis epidemics. In order to achieve the goals of the *National HIV/AIDS Strategy: Updated to 2020* and the *Viral Hepatitis Action Plan,* funding must be robust for prevention and care programs. Domestic prevention efforts must match the commitment to the care and treatment of people living with HIV (PLWH). To be successful, we must expand traditional efforts and scale-up proven new biomedical prevention modalities such as treatment as prevention, while reimaging how the

compendium of effective prevention tools can work in tandem to curb incidence in the U.S. We must also prioritize funding and efforts to the populations disproportionately impacted by HIV in the U.S. – especially men who have sex with men (MSM) of color. Among the services necessary to improve health outcomes are the needs for linkage to and retention in care, and access to medications that suppress viral load, which make HIV more difficult to transmit – ultimately leading to fewer new infections. The Centers for Disease Control and Prevention's (CDC) prevention programs and the Ryan White Program are crucial to preventing new infections and improving health outcomes.

Even with the continued implementation of the Affordable Care Act (ACA), public health remains a critical in meeting the needs of the hardest to reach, most vulnerable populations (e.g., MSM, youth, persons who inject drugs) from actively identifying and locating persons at risk, to ensuring linkage to and retention in medical care in a manner that is responsive to the needs of PLWH and/or hepatitis. While the ACA provides opportunities to increase access for many PLWH and/or hepatitis to the care and prevention services needed to help end these twin epidemics, access to insurance alone does not replace the key role of state public health programs to monitor diseases within their borders.

HIV/AIDS Care and Treatment Programs

The Health Resources and Services Administration (HRSA) administers the $2.3 billion Ryan White Program that provides health and support services to more than 500,000 people living with HIV (PLWH). NASTAD requests a minimum increase of **$65.3 million** in FY2017 for state Ryan White Part B grants, including an increase of **$22.3 million** for Part B and **$43 million** for AIDS Drug Assistance Programs (ADAPs). The Ryan White Part B Program funds state health departments to provide care, treatment, and support services for low-income uninsured and underinsured individuals living with HIV. With these funds states and territories

provide access to HIV clinicians, life-saving and life-extending therapies, and a full range of vital coverage completion services to ensure adherence to complex treatment regimens. The state ADAPs provide medications to low-income PLWH who have limited or no coverage from private insurance, Medicare, and/or Medicaid. Health departments are creating new infrastructure and leveraging existing systems to ensure continuous, high quality care for PLWH. The Ryan White Program continues to serve PLWH in order to ensure that clients do not experience gaps in coverage or access to treatment.

HIV/AIDS Prevention and Surveillance Programs

NASTAD requests an increase of **$67 million** in FY2017 for CDC's Division of HIV Prevention (DHAP). The flagship HIV prevention program, HIV Prevention by Health Departments, funds state and local health departments to provide the foundation for HIV prevention and control nationwide. Health departments are the cornerstone implementers of federal public health policy and are essential to lowering HIV infections. HIV prevention activities and services are targeted to communities where HIV is most heavily concentrated, particularly among racial and ethnic minorities and gay men/MSM of all races and ethnicities.

The number of new HIV infections must decrease in order to see meaningful improvements in individual and community level health outcomes, particularly among disproportionately impacted populations. Of the 1.2 million PLWH, currently, 14% are unaware of their infection therefore unable to access adequate care. Furthermore, it is increasingly clear that early detection, linkage to and retention in care, and adherence to treatment will suppress individual and community viral loads and reduce the incidence of HIV. Addressing interventions along the HIV care continuum is our newest and most effective tool to reduce HIV infections; however, health departments need additional support to successfully implement these strategies.

Pre-exposure prophylaxis (PrEP) is a prevention method where a HIV-negative individual takes a daily pill to prevent the acquisition of HIV. Currently, there is limited categorical funding within public health programs to pay for the medication and costs associated with assessment and care engagement of PrEP clients. Often, these patients are among populations being disproportionately impacted by HIV. For these reasons, there needs to be appropriate funding streams for expanding PrEP implementation in public health settings and to provide technical assistance to health departments. NASTAD supports the demonstration project proposed in the President's Budget that would allow health departments to purchase PrEP and provide other supportive services.

Robust surveillance systems are essential for high-impact prevention, including using surveillance data for program planning and response, strategically directing resources to populations and geographic areas, and linking and retaining individuals in care. Additional resources will allow improvements in core surveillance and expand surveillance for HIV incidence, behavioral risk, and receipt of point of care information. This will, in turn, contribute to improved testing and linkage to care, retention and re-engagement in care, and reducing risk behaviors.

NASTAD requests that the Committee continue to allow states and localities the discretion to use federal funds to support cost-effective and scientifically proven, syringe services programs (SSPs), which lower HIV and hepatitis infection rates, reduce use of illegal drugs, and help connect people to HIV and hepatitis medical treatment, including substance abuse treatment.

Viral Hepatitis Prevention Programs

NASTAD requests an increase of **$23.8 million** in FY2017 for the CDC's Division of Viral Hepatitis (DVH). This increase will better enable state and local health departments to

provide the basic, core public health services to combat hepatitis, increase surveillance, testing and education efforts nationwide. NASTAD requests that CDC dedicate at least **$14.5 million** for the viral hepatitis prevention coordinators (VHPC) program to support and expand programs in all existing jurisdictions. The IOM report and the *Viral Hepatitis Action Plan*, set prevention goals, established program priorities and assigned responsibilities for actions to HHS operating divisions, including CDC. In turn, CDC has provided funds to state and local health departments to coordinate prevention and surveillance efforts via the VHPC.

For over a decade, the VHPC program has been and remains the only national program dedicated to the prevention and control of the hepatitis epidemics. The CDC has estimated that up to 5.3 million people are living with hepatitis B (HBV) and/or hepatitis C (HCV) in the U.S. and as much as 75% are not aware of their infection. Additionally, recent alarming epidemiologic reports indicate a rise in HCV infection among young people throughout the country. Some jurisdictions have noted that the number of people ages 15 to 29 being diagnosed with HCV infection now exceeds the number of people diagnosed in all other age groups combined - a trend that is following the prescription drug overdose epidemic and increasing use of heroin in rural and suburban areas. NASTAD encourages the committee to prioritize disproportionately impacted populations and increase funding for primary prevention efforts.

As you contemplate the FY2017 Labor-Health-Education Appropriations bill, we ask that you consider all of these critical funding needs. We thank the Chairman, Ranking Member, and members of the Subcommittee, for their thoughtful consideration of our recommendations. Our response to the HIV and hepatitis epidemics in the U.S. defines us as a society, as public health agencies, and as individuals living in this country. There is no time to waste in our nation's continued fight against these epidemics.

Meals on Wheels, Inc. *Serving Central Indiana* P.O Box 40969, Indianapolis, IN 46240
ph 317 252 5558 *fx* 317 252 5559 ***email*** info@mealsonwheelsindy.org **www.mealsonwheelsindy.org**

Testimony Prepared by Barb Morris, Executive Director & CEO of Meals on Wheels of Central Indiana for the United State House Subcommittee on Labor, Health and Human Services, Education, and Related Agencies addressed to the Department of Health and Human Services

April 15, 2016

Meals on Wheels of Central Indiana is part of a nationwide coalition, the Food is Medicine Coalition, of food and nutrition services providers, affiliates and their supporters across the country that provide food and nutrition services to people living with HIV/AIDS (PWH) and other chronic illnesses. In our service area, we deliver 260,000 medically tailored meals to adult day centers and homes annually. Collectively, the Food is Medicine Coalition is committed to increasing awareness of the essential role that food and nutrition services (FNS) play in successfully treating HIV/AIDS and to expanding access to this indispensable intervention for people living with other severe illnesses.

1.) Why Food and Nutrition Services (FNS) Matter for PWH

While adequate food and nutrition are basic to maintaining health for all persons, good nutrition is crucial for the management of HIV infection. Proper nutrition is needed to increase absorption of medication, reduce side effects, and maintain healthy body weight. Research has identified the virus as an independent risk factor for cardiovascular, liver and kidney disease, cancer, osteoporosis and stroke. Several HIV medications can cause nausea and vomiting and some can affect lab results that test lipids and kidney and liver function. These compounding health effects, caused by the virus and its medications, reinforce the important role a nutrient-rich diet plays in a patient's overall care plan. In addition, providing food and nutrition services can serve to facilitate access and engagement with medical care, especially among vulnerable populations.

The Food and Nutrition Services category within the Ryan White Program includes medical nutritional therapy (MNT) and food and nutrition services (FNS). MNT covers nutritional diagnostic, therapy, and counseling services focused on prevention, delay or management of diseases and conditions, and involves an in-depth assessment, periodic reassessment and intervention provided by a licensed, Registered Dietitian Nutritionist (RDN) outside of a primary care visit. The range of FNS provided through the Ryan White program complements the needs of PWH at any stage of their illness. For those who are most mobile, there are congregate meals, walk-in food pantries and voucher programs. For those whose disease has progressed, home-delivered meals and home-delivered grocery bags complement their medical treatment.

Since 2006, HRSA has included MNT and FNS, provided under the guidance of RDNs, as a clinically effective **core medical service** in the Ryan White Program. These services play a critical role in ensuring that PWH enter and continue in primary medical care, adhere to their medications, and ultimately achieve viral suppression.

2.) FNS as a Care Completion Service Unique to Ryan White

Social and economic interventions, most often in the form of care completion service like food and nutrition services, are fundamental to making health care work for PWH. Support services for PWH are not covered in any comprehensive way by Medicaid or other public insurance initiatives that have been expanded by the Affordable Care Act. As the HIV epidemic in the United States increasingly impacts low-income individuals, support services help stabilize individuals living with or at risk of HIV. When needs are met, and life's emergencies are held at bay, PWH are poised to remain connected to care and treatment.

3.) Access to FNS and the Triple Aim

Access to appropriate food and nutrition services (FNS) are increasingly recognized as key to accomplishing the triple aim of national healthcare reform for PWH.

Better Health Outcomes

When clients get effective FNS and become food secure, they then keep scheduled primary care visits, score higher on health functioning, are at lower risk for inpatient hospital stays and are more likely to take their medicines[i]. Studies show both the health benefits of access to MNT and/or nutrition counseling for people with HIV infections[ii] and the resulting decreases in their healthcare costs. Compare these outcomes to PWH who are food insecure, who have:

- Lower CD4 counts & lower likelihoods of having undetectable viral loads[iii]
- More ER visits[iv] & increased morbidity and mortality[v]
- More missed primary care appointments & reduced use of antiretroviral therapy[vi].

Lower Healthcare Costs

Millions of dollars in healthcare expenditures are saved through the provision of FNS to PWH. A recent study comparing participants in a medically-tailored FNS program vs. a control group within a local managed care organization found that average monthly healthcare costs for PWH fell 80% in first three months after receiving FNS[vii]. If hospitalized, nourished clients' costs were 30% lower, their hospital length of stay was cut by 37% and they were 20% more likely to be able to be discharged to their homes rather than a more expensive institution[viii]. Furthermore, FNS are a very inexpensive intervention. For each day in a hospital saved, you can feed a person a medically-tailored diet for half a year.

Improved Patient Satisfaction

Studies show nutrition counseling improves quality of life[ix]. Members overwhelmingly report that our services help them live more independently, eat more nutritiously and manage their medical treatment more effectively.

4.) FNS and the National HIV/AIDS Strategy (NHAS)

Access to FNS for PWH is fundamental to fulfilling the goals of the NHAS.

- **NHAS Goal: Reducing new HIV infections:** PWH who are food insecure are less likely to have undetectable viral loads in a statistically significant way. Undetectable viral loads prevent transmission 96% of the time[x], thus, FNS is key to prevention[xi].

NHAS Goal: Reducing new HIV infections: PWH who are food insecure are less likely to have undetectable viral loads in a statistically significant way. Undetectable viral loads prevent transmission 96% of the time[x], thus, FNS is key to prevention[xi].

- **NHAS Goal: Increasing access to care and improving health outcomes for people living with HIV:** PWH who receive effective FNS are more likely to keep scheduled primary care visits, score higher on health functioning, are at lower risk for inpatient hospital stays and are more likely to take their medicines[xii].
- **NHAS Goal: Reducing HIV-related disparities and health inequities:** By providing FNS to PWH who are in need largely because of poverty, we improve health outcomes, thereby reducing health disparities[xiii].
- **NHAS Goal: Achieving a more coordinated national response to the HIV epidemic:** There remains a tremendous variation by state in coverage of food and nutrition services both inside and outside of Ryan White, making support for Ryan White HIV Program all the more needed. Ultimately, if we are going to achieve a more coordinated national response to the HIV epidemic and our quest to reduce healthcare spending nationwide, FNS must be included in all healthcare reform efforts, including Ryan White and the ACA.

Conclusion

We are deeply aware of the difficult decisions that face the members of the Committee in the current fiscal environment. Yet, research shows that investment in FNS, with the great return in prevention and retention in HIV care, are vital to lowering the number of new infections in the domestic HIV epidemic and ultimately reducing healthcare costs and preserving healthcare resources for the future. A client's diet can literally have life and death consequences. When people are severely ill, good nutrition is one of the first things to deteriorate, making recovery and stabilization that much harder, if not impossible. Early and reliable access to medically-appropriate FNS helps PWH live healthy and productive lives, produces better overall health outcomes and reduces health care costs.

Along with our colleagues, we appreciate the opportunity to offer this testimony regarding the FY 2017 Appropriations process. We are also pleased to offer our assistance and expertise, including information from our Research Library.

Thank you.

Barb Morris
Executive Director & CEO
Meals on Wheels of Central Indiana
708 E. Michigan Street
Indianapolis, IN 46202

[ii] Academy of Nutrition and Dietetics (formerly American Dietetic Association). HIV/AIDS Nutrition Evidence Analysis Project at http://www.adaevidencelibrary.com/conclusion.cfm?conclusion_statement_id=250707 Accessed 29 July 2012.

[iii] Aidala A., Yomogida M., and the HIV Food & Nutrition Study Team (2011); Singe AW,Weiser SD, McCoy, SI. Does Food Insecurity Undermine Adherence to Antiretroviral Therapy? A Systematic Review. AIDS Behav (2015) 19:1510–1526.

[iv] Ibid.

[v] Anema A, Chan K, Yip B, Weiser S, Montaner JSG, Hogg RS. Impact of food insecurity on survival among HIV-positive injection drug users receiving antiretroviral therapy in a Canadian cohort. 141st APHA Annual Meeting, Nov. 2-6, 2013. Boston, MA. Abstract #: 290277

[vi] Aidala A., Yomogida M., and the HIV Food & Nutrition Study Team (2011).

[vii] Gurvey J, Rand K, Daugherty S, Dinger C, Schmeling J, Laverty N. Examining Health Care Costs Among MANNA Clients and a Comparison Group. J Prim Care Community Health. (2013) 4:311-317

[viii]Ibid.

[ix] Rabeneck L, Palmer A, Knowles JB, Seidehamel RJ, Harris CL, Merkel KL, Risser JMH, Akrabawi SS. A randomized controlled trial evaluating nutrition counseling with or without oral supplementation in malnourished HIV-infected patients. J Am Diet Assoc. (1998) 98: 434-438;Schwenk A, Steuck H, Kremer G. Oral supplements as adjunctive treatment to nutritional counseling in malnourished HIV-infected patients: randomized controlled trial. Clinical Nutrition (1999) 18(6): 371-374.

[x] M. S. Cohen *et al.*, Prevention of HIV-1 Infection with Early Antiretroviral Therapy. N. Engl. J. Med.(2011) 365, 493-505 . HPTN 052

[xi] Palar K, Laraia B, Tsai A, Weiser SD Food insecurity is associated with sexually transmitted infections and HIV serostatus among low income adults in the National Health and Nutrition Examination Survey (NHANES) (1999-2010). Presented at the American Public Health Association 141st Annual Meeting, Boston, MA, November 5, 2013.

[xii] Aidala A, Yomogida M, Vardy Y & the Food & Nutrition Study Team. Food and Nutrition Services, HIV Medical Care, and Health Outcomes. New York State Department of Health: Resources for Ending the Epidemic, 2014. Available at

xiii Weiser SD, Frongillo EA, Ragland K, Hogg RS, Riley ED, Bangsberg DR. Food insecurity is associated with incomplete HIV RNA suppression among homeless and marginally housed HIV-infected individuals in San Francisco. J Gen Intern Med. (2009) 24(1):14-20.

WITNESSES

	Page
ARVO	138
Ad Hoc Group for Medical Research	834
Aldrighetti, Rino	801
Alpha–1 Foundation	520
American Academy of Family Physicians	431
American Academy of PA's	489
American Association of Anesthesiologists	470
American College of Preventive Medicine	575
American Dental Education Association	14
American Geriatrics Society	620
American Heart Association	45
American Indian Higher Education Consortium	850
American Mosquito Control Association	693
American Psychiatric Association	558
American Psychological Association	650
American Society of Nephrology	897
American Society of Hematology	30
Amundson, Sara	641
Armour, Tim	775
Arthritis Foundation	600
Association of American Cancer Institutes	308
Association of American Medical Colleges	388
Association of Independent Research Institutes	534
Ayoub, Richard	767
Ball, Brandon	551
Barcal, Heather	313
Baumberg, James	689
Bavier, Anne R.	157
Benjamin, Geoerges C.	342
Bennewith, Alexandra	724
Bens, Cynthia	830
Benson, Ruby J.	739
Berenbaum, May	273
Bischoff, Kim	127
Blancato, Robert	39, 420
Bonta, Paul	699
Brain Injury Association of America	211
Branen, Tom	438
Brill, Alexa	235
Brooks, Harold	904
Brooks, Kelli	260
Buckland, Kelly	196
Buckley, Gerard	245
Burda, Nicole	298
Butler, Lisa	677
Byram, Luke	218
Campbell, Preston W.	1
Carmical, Donna	102
Carter, Jeff	571
Castaldo, Anthony	806
Charles, Frances G.	717
Children's Hospital Association	713
Claassen, Lee	616
Clapp, Robert	822

Page

Clarrage, Mel 474
Coalition of Northeastern Governors 34
Coats, John T. 242
Coffey, Darla 97
Coleman, Clare 351
Coleman, Diane 257
Conrad, Gregory E. 54
Consortium of Social Science Associations 544
Cooper, Ann 517
Cortes, Alberto 482
Daugherty, Sue 269
Davies, Pam 450
de Stacy Harrison, Patricia 84
DeWitt, Stephen 318
Desravines, Jean 789
Dewey, William L. 5, 922
Di Lorenzo, Carlo 586
Dickinson, Jeff 755
Dickman, Martin 303
Dreyer, Benard 106
Duval, Laura 329
Easter Seals 116
Elzy, Chrissy 760
Emergency Nurses Association 465
Farley, Jenny 263
Favuzzi, Teresa 765
Federation of American Scientists 41
Ferracane, Jack 253
Fey, Rachel 675
Food Bank of Contra Costa 736
Foti, Margaret 25
Freeman, Lori 860
Frost, Jared 526
Fults, Debra 325
Fuschillo, Charles J. 436
Gallucci, Marc Anthony 671
Gandy, Kim 881
Gavlak, Gina 866
George, Jeremy 36
Gilberti, Mary 818
Grant, Sonia 214
Grassi, Mary 919
Gustafson, Patti 70
HIV Medicine Association 357
Hall, R. Shannon 926
Halog, Ron 549
Hamburg, Richard 123
Harding, Cliff 221
Hawkins, Daniel 493
Health Professionals and Nursing Education Coalition 507
Healy, Eileen 531
Hennenfent, Mike 763
Hieshetter, Janet 667
Hinze, Fiona 276
Hoeksema, Mary Jo 416
Hollander, Ellie 703
Hoppert, Donald 521
Horner, Sharon 378
Hostler, Monika 403
Hovelson, Tiffany 371
Humane Society of the United States 642
Infectious Diseases Society of America 460
Institute of Makers of Explosives 76
Jauregui, Ben 335
Jedrziewski, Kathryn 152
Johnson, Mariah 747
Kagan, Jill 383
Keen, Linda A. 188

Page

Kibbee, Lou Ann 686
Kilmer, Jacquelyn 624
Kindel, Mary Ann 226
Kirk, Diane T. 185
Kochler, Micah el 645
Kosier, Patt 173
Kranz, Dory 797
Kronenberg, Henry 426
LEAD 512
Lacy, James 893
Lang, William 411
Langman, Mary M. 9
Leach, Caitlin 355
Lee, Jennifer 921
Lesley, Bruce 629
Levine, Felice 752
Liwbenow, Anna 315
Lott, Laura 930
Lundebjerg, Nancy 771
Lyons, Kat 369
Malhotra, Atul 870
Mancera, Claudia 696
Maniatis, Tom 50
March of Dimes 655
Marottolo, Carmen 364
Martinelli, Julia 327
McDermott, Daniel 231
McDonald, Leander 93
McKown, Robert 648
Miller, Michele 189
Miyamato, Suzanne 632
Moffitt, Robert 132
Molina, Patricia 68
Momon, Pamela 757
Moore, Nuala 864
Moraras, Kate 876
Morris, Barb 939
Morris, Brent 380
Morton, Erin Will 165
Myers, Matthew L. 119
NACCHO 825
NAEVR 147
Nathanson, Rebecca 456
National Academies of the Sciences 748
National Congress of American Indians 567
National Energy Assistance Directors' Association 663
National Indian Health Board 606
National Kidney Foundation 452
National Minority Consortia 331
National Rural Health Association 293
Nevarez, Arturo 193
O'Shaughnessy, Patrick 288
Oregon State Independent Living Council 874
PEW Charitable Trusts 854
PRevent Blindness 886
Painter, Ronald 596
Panetta, Joe 57
Paus, Kristin 250
Pearl, Karen 392, 503
Peel, Ann D. 374
Penner, Murray 934
Perez, Daniel Paul 708
Perschon, Kate 448
Physician Assistant Education Association 80
Proskauer, Charmain 900
Pulling, Erin 838
Quintana, Juan 88
Railroad Retirement Board 64

Page

Raimondi, Mary Pat 207
Raines, Curtis 171
Raymond, Daniel 582
Reamer, Andrew 743
Rethman, Jill 111
Rhoads, Kay 143, 347
Riggs, Robert 814
Riksen, Michael 360
Robbins, Scott 162
Rock, Anthony F. 337
Ruzenski, Susan 20
Schlesinger, Arthur 18
Schmid, Carl 477
Selker, Harry P. 793
Shaffer, Todd 909
Shannon, Stephen 591
Sheketoff, Emily 720
Shniderman, Craig 284
Shriver, Mark 498
Smith, Donna 176
Smith, Laren C. 266
Smith, William 398
Smokler, Irving 659
Spady, Tyrone C. 59
Spahn, Kathy 486
Sprenkel, Mary Ellen 555
Teasdale, Thomas A. 578
Thomas, Sheila 169
Thornton, Alice 279
Tomlinson, Lisa 914
Trautman, Deborah 562
Tringali, Glenn 396
Truett, Brett 406
Turnbull, Ivy 443
Twaddell, Jim 857
VOR 71
Van Doren, Lisa 785
Vargas, Maria 414
Vaughn, Susan 135
Vehrs, Kristin 191
Vinci, Yasmina 726
Vose, Julie 320
Warburton, Michael 201
Wardle, Denise 232
Warsinskey, Richard E. 422
Waters, David 238
Weamer, Michael 808
WestCare Foundation 539
Whited, William 846
Williams, Amber 611
Wimmer, Harold 637
Wimmer, Harold 889
Witherspoon, Nsedu Obot 731

○