



April 26, 2019

The Honorable Nita M. Lowey
Chairman
Committee on Appropriations

The Honorable Kay Granger
Ranking Member
Committee on Appropriations

The Honorable Rosa DeLauro
Chairman
Committee on Appropriations
Subcommittee on Labor, HHS & Education

The Honorable Tom Cole
Ranking Member
Committee on Appropriations
Subcommittee on Labor, HHS & Education

The Honorable Sanford Bishop, Jr.
Chairman
Committee on Appropriations
Subcommittee on Agriculture & FDA

The Honorable Jeff Fortenberry
Ranking Member
Committee on Appropriations
Subcommittee on Agriculture & FDA

The Honorable José Serrano
Chairman
Committee on Appropriations
Subcommittee on Commerce, Justice,
Science

The Honorable Robert Aderholt
Ranking Member
Committee on Appropriations
Subcommittee on Commerce, Justice,
Science

by electronic delivery

Dear Chairman Lowey, Vice Chairman Granger, Chairman DeLauro and Ranking Member Cole, Chairman Bishop and Ranking Member Fortenberry, Chairman Serrano and Ranking Member Aderholt:

We sincerely thank you for recognizing and decisively responding to the challenges of Alzheimer's disease and other forms of dementia (including vascular, Lewy body dementia and frontotemporal degeneration) by passing the Fiscal Year 2019 (FY19) appropriations with a historic funding increase for Alzheimer's research. We applaud your continued 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.

As you work to construct Fiscal Year 2020 (FY20) appropriations bills, we respectfully encourage you to continue the momentum toward the National Alzheimer's Plan goals and your own commitment to advancing science, care, and support. **Specifically, we request that the FY20 appropriations bills include at least the following minimum increases:**

- a **\$350 million increase for National Institutes of Health (NIH) research on Alzheimer's disease and other forms of dementia to accelerate progress as articulated in the Bypass Budget Proposal for Fiscal Year 2020**
- a **\$500 million increase for aging research across the NIH, in addition to the funding for dementia-specific research**, to ensure that the NIH has the resources to address the many other age-related chronic diseases that affect people with dementia
- a **\$2.5 billion increase for the NIH, including funds from the 21st Century Cures Act for targeted initiatives**
- a **\$418 million increase for the Food and Drug Administration (FDA), in addition to funds included in the 21st Century Cures Act for targeted initiatives**
- a **12% increase for Older Americans Act (OAA) services including, but not limited to:**
 - a **\$21.75 million increase for the OAA Title III E National Family Caregiver Support Program**
 - a **\$59.4 million increase for the OAA Title III C-1 Congregate Meals Program**
 - a **\$30.2 million increase for the III C-2 Home-Delivered Meals Program**
 - a **\$5 million increase for the OAA Title IV Falls Prevention Program**
- a **\$900,000 increase for the Lifespan Respite Care Program**
- a **\$6.5 million increase for the Alzheimer's Disease Program Initiative**
- a **\$3 million increase for the DoJ Missing Alzheimer's Disease Alert Program**
- **\$20 million in new funds for the CDC to implement the BOLD Act**

There are few more compelling or complex issues to confront our aging society, now and over the coming decades, than Alzheimer's disease and other forms of dementia. These neurodegenerative conditions impose enormous costs to our nation's health, prosperity, and social fabric, costs that are skyrocketing.ⁱ Based on the National Institute on Aging's Health and Retirement Study (HRS), we know that the health system costs of caring for people with dementia in the United States are comparable to, and perhaps greater than, those for heart disease and cancer.ⁱⁱ A recent analysis of HRS data revealed that average per-person health care spending in the last five years of life for people with dementia was more than \$250,000 -- 57 percent greater than costs associated with death from other diseases including cancer and heart disease.ⁱⁱⁱ

Currently, more than 5.8 million Americans are living with dementia at an annual cost to our economy exceeding \$290 billion.^{iv} An estimated 16 million Americans provide unpaid care for someone with dementia, resulting in additional healthcare and economic costs for the family caregiver. Alzheimer's disease contributes to the deaths of approximately

500,000 Americans each year. Alzheimer's disease is the third leading cause of death in the United States^v and — despite a powerful body of evidence for risk-reduction strategies,^{vi} which is being expanded with significant NIH investments^{vii} — the only one among the top 10 for which there is not yet a proven means of prevention, disease modification or cure.^{viii}

Today, another person develops the disease every 65 seconds; by 2050, someone in the United States will develop the disease every 33 seconds. This explosive growth will cause Alzheimer's costs to increase from an estimated \$290 billion in 2019 to \$1.1 trillion in 2050 (in 2019 dollars).^{ix} The federal government, through Medicare and Medicaid payments, shoulders an estimated 70 percent of all such direct care costs. These mounting costs threaten to bankrupt families, businesses and our health care system.

We support a \$350 million increase for National Institutes of Health (NIH) research on Alzheimer's disease and other forms of dementia to accelerate progress as articulated in the Bypass Budget Proposal for Fiscal Year 2020,^x and a \$500 million increase for aging research across the NIH in addition to the funding for dementia-specific research, to ensure that the NIH has the resources to address the many other age-related chronic diseases that affect people with dementia. 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.^{xi}

Due to leadership and direction from Congress, the Department of Health and Human Services (HHS) continues to increase prioritization of Alzheimer's disease and other forms of dementia. 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.^{xii} The Food and Drug Administration is encouraging new research avenues and clarifying regulatory approval pathways.^{xiii} Your appropriations committee and NIH have moved mountains to create additional resources, public-private partnerships, and a culture of urgency. Across the NIH, institutes are advancing promising research into Alzheimer's disease and other forms of dementia to: understand genetic risk factors; address health disparities among women, African Americans, Hispanics, and persons with intellectual and developmental disabilities; understand Down syndrome's relationship to Alzheimer's disease; pursue cutting-edge trials aimed at preventing or substantially slowing disease progression by administering treatments much earlier in the disease process; and improve quality of life for people with dementia and their caregivers.^{xiv} NIH and its partners are hard at work implementing the new *National Strategy for Recruitment and Participation in Alzheimer's and Related Dementias Clinical Research*,^{xv} which will engage broad segments of the public in the Alzheimer's and related dementias research enterprise, with a particular focus on underrepresented communities, so that studies with an aim to better understand and eventually cure these disorders can successfully and more quickly enroll and retain individuals. In FY20, the National Institute on Aging (NIA) plans to increase its research

focus on Molecular Pathogenesis and Pathophysiology of Alzheimer's Disease; Diagnosis, Assessment, and Disease Monitoring; Translational Research and Clinical Interventions; Epidemiology; and Care and Caregiver Support.^{xvi}

We support the recommendation from the Ad Hoc Group on Medical Research to appropriate at least \$41.6 billion in FY20 for the NIH, including funds provided through the 21st Century Cures Act for targeted initiatives. This funding level, endorsed by well over 200 members of the U.S. House,^{xvii} would continue a trajectory of steady and predictable annual increases – allowing for meaningful growth above inflation in the base budget that would expand NIH's capacity to support promising science in all disciplines – and would ensure that the Innovation Account supplements the agency's base budget, as intended, through dedicated funding for specific programs.

We support the recommendation from the Alliance for a Stronger FDA to appropriate at least \$3.485 billion in FY20 for the FDA, including the President's request for \$418 million in additional spending on medical products and food safety programs. Funding would strengthen FDA systems that guide and support agency decision-making and stimulate innovation for medical products, including improvements in drug and device manufacturing, advances in the use of real world evidence in medical product development, revisions to the regulatory framework for digital health technology, enhancements to research on rare diseases such as less common forms of dementia, and new systems that could speed the introduction of cost-saving generic drugs.

We support the recommendation from the Leadership Council of Aging Organizations (LCAO) for a 12% increase for Older Americans Act services, a \$900,000 increase for the Lifespan Respite Care Program, and a \$6.5 million increase for the Alzheimer's Disease Program Initiative. These investments are relatively small but crucial complements to vastly larger Medicaid and Medicare expenditures to protect and promote the wellbeing of people living with dementia and their caregivers. As urgently as resources are needed to enable scientific breakthroughs, the millions of Americans currently living with dementia and their family caregivers deserve strengthened commitments to programs to protect and enhance their quality of life. The World Health Organization has noted that dementia is among the leading causes of disability and dependence among older people.^{xviii} Federal programs and initiatives have a vital role in helping people receive a diagnosis so they know what they are facing, can begin disability and care planning processes, maintain independence as long as possible, and – for people with younger onset dementia – seek appropriate workplace accommodations. We commend your work in FY19 to protect and support the CDC Alzheimer's disease health promotion program, the Lifespan Respite Care program, the ACL Alzheimer's Disease Program Initiative, the National Family Caregiver Support Program, falls prevention programs, and congregate and home-delivered meals programs. We encourage you to provide substantial new funding in FY20 to sustain core Older Americans Act services and to develop and disseminate services instrumental to achieving the national plan's goals to enhance care quality, efficiency and expand supports.^{xix} These programs provide essential respite, training, and support to help family caregivers meet the needs of persons living with dementia.

The Administration for Community Living (ACL) Alzheimer's Disease Program Initiative (ADPI) supports and promotes the development and expansion of dementia-capable home and community-based service long-term services and support systems in states

and communities. ADPI delivers cutting-edge programs that meet the needs of individuals and caregivers managing dementia. Part of those resources support ACL's National Alzheimer's and Dementia Resource Center (NADRC) based at RTI International. NADRC provides technical assistance to ACL's grantees that build dementia-capable systems to better identify and support people with dementia living in the community and improve training for dementia caregivers who suffer from considerable stress and depression. Many of the programs are geared towards at-risk dementia populations, such as those who live alone, those with disabilities and those who reside in rural, poor and minority communities. NADRC also produces dementia-related toolkits and provides technical assistance and webinars on Alzheimer's and other dementias to the public.^{xx}

We support a \$3 million increase -- \$5 million in total funding – for the Department of Justice (DoJ) Missing Alzheimer's Disease Patient Alert Program, which provides grants for training and technology that help first responders locate people living with Alzheimer's disease or autism who wander become lost. The program saves lives, strengthens the capacity of search and rescue programs to respond to other community needs, and allows local first responders to conserve both time and money. The program's strong track record, along with rapid growth in the number of people living with dementia and the program's recent expansion to include services for people living with autism, merit and require substantial addition resources to better serve states and communities nationwide.

Until an effective treatment to prevent, slow or cure dementia comes to market, families and friends rely on these programs to protect their own well-being while helping persons with dementia to remain independent and in the community while delaying placement in institutional settings.

The CDC's Healthy Brain Initiative has launched its 2018-2023 Healthy Brain Aging Road Map to ramp up the nation's public health capacity in addressing dementia; the companion Road Map for Indian Country will launch soon.^{xxi} The Road Map will advance strategies to reduce lifestyle risk factors, improve detection and diagnosis, strengthen community supports for people with dementia and their families, and redress health disparities.

In addition to needed increases in core funding for the CDC's long-standing and successful Healthy Brain Initiative, **we support a new \$20 million appropriation for CDC to implement the Building Our Largest Dementia (BOLD) Infrastructure for Alzheimer's Act (Pub. L. 115 – 406).**^{xxii} Under the law, Congress has directed CDC to strengthen the public health infrastructure nationwide by implementing effective Alzheimer's interventions focused on public health priorities including increasing early detection and diagnosis, reducing modifiable risk, and preventing avoidable hospitalizations. Congress authorized \$100 million over five years – beginning in FY20 – so that CDC would have the necessary resources to establish Alzheimer's and Related Dementias Public Health Centers of Excellence, provide funding to state, local, and tribal public health departments, and increase data analysis and timely reporting.

Thank you for considering our views and for your commitment to overcoming Alzheimer's disease and other forms of dementia. For any questions or additional information about this legislation or other policy issues, please contact Ian Kremer,

executive director of Leaders Engaged on Alzheimer's Disease (the LEAD Coalition),^{xxiii}
ikremer@leadcoalition.org or (571) 383-9916.

Sincerely,

ACADIA Pharmaceuticals
Accelerate Cure/Treatments for
Alzheimer's Disease (ACT-AD)
Coalition
ActivistsAgainstAlzheimer's Network
African American Network Against
Alzheimer's
Aging and Memory Disorder Programs,
Howard University
Aging Life Care Association®
Paul S. Aisen, MD (Keck School of
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Therapeutic Research Institute*)
Alliance for Aging Research
Alliance for Patient Access
Alzheimer's Alliance, Michigan State
University
Alzheimer's & Dementia Alliance of
Wisconsin
Alzheimer's Drug Discovery Foundation
Alzheimer's Foundation of America
Alzheimer's Los Angeles
Alzheimer's Mississippi
Alzheimer's New Jersey
Alzheimer's Orange County
Alzheimer's San Diego
Alzheimer's Tennessee
Alzheimer's Texas
American Academy of Neurology
American Association for Geriatric
Psychiatry
American Federation for Aging Research
(AFAR)
American Geriatrics Society

American Medical Women's Association
American Society of Consultant
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Caregiver Action Network

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 ClergyAgainstAlzheimer's Network
 Cleveland Clinic Foundation
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Latino Alzheimer's and Memory Disorders Alliance

LatinosAgainstAlzheimer's

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LeadingAge

Lewy Body Dementia Association

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Linked Senior, Inc

Livpact Inc.

Lou Ruvo Center for Brain Health

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Medicare Rights Center

Minnesota Association of Area Agencies on Aging

Minnesota Brain Aging Research Collaborative

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Mount Sinai Center for Cognitive Health

National Alliance for Caregiving (Mike Wittke)

National Asian Pacific Center on Aging

National Association of Activity Professionals

National Association of Chronic Disease Directors

National Association of Counties (NACo)

National Association of State Long-Term Care Ombudsman Programs (NASOP)

National Association of States United for Aging and Disabilities

National Caucus and Center on Black Aged, Inc. (NCBA)

National Certification Council for Activity Professionals

National Consumer Voice for Quality Long-Term Care

National Council for Behavioral Health

National Down Syndrome Society

National Hispanic Council On Aging (NHCOA)

National Task Group on Intellectual Disabilities and Dementia Practices

NFL Neurological Center

NYU Alzheimer's Disease Center

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The Ohio Council for Cognitive Health	The Youth Movement Against Alzheimer's
Pat Summitt Foundation	
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** Affiliations of individual researchers are for identification purposes only and do not necessarily represent the endorsement of affiliated institutions.*

ⁱ <http://www.nejm.org/doi/full/10.1056/NEJMsa1204629>

ⁱⁱ <http://www.nejm.org/doi/full/10.1056/NEJMsa1204629>

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- xv <https://www.nia.nih.gov/sites/default/files/2018-10/alzheimers-disease-recruitment-strategy-final.pdf>
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- xix <https://aspe.hhs.gov/system/files/pdf/102526/NatlPlan2012%20with%20Note.pdf>
- xx <https://nadrc.acl.gov>
- xxi <https://www.cdc.gov/aging/healthybrain/roadmap.htm>
- xxii <https://www.congress.gov/bill/115th-congress/senate-bill/2076>
- xxiii <http://www.leadcoalition.org> Leaders Engaged on Alzheimer's Disease (the LEAD Coalition) is a diverse national coalition of member organizations including patient advocacy and voluntary health non-profits, philanthropies and foundations, trade and professional associations, academic research and clinical institutions, and home and residential care providers, large health systems, and biotechnology and pharmaceutical companies. The LEAD Coalition works collaboratively to focus the nation's strategic attention on dementia in all its causes -- including Alzheimer's disease, vascular disease, Lewy body dementia, and frontotemporal degeneration -- and to accelerate transformational progress in detection and diagnosis, care and support, and research leading to prevention, effective treatment and eventual cure. One or more participants may have a financial interest in the subjects addressed.