



March 22, 2017

The Honorable Rodney P. Frelinghuysen
Chairman
Committee on Appropriations
H-305 The Capitol
Washington, DC 25015

The Honorable Nita M. 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
2467 Rayburn House Office Building
Washington, D.C. 20515

The Honorable Rosa DeLauro
Ranking Member
Committee on Appropriations
Subcommittee on Labor, HHS & Education
2413 Rayburn House Office Building
Washington, D.C. 20515

The Honorable Robert Aderholt
Chairman
Committee on Appropriations
Subcommittee on Agriculture & FDA
235 Cannon Office Building
Washington, DC 20515

The Honorable Sanford Bishop
Ranking Member
Committee on Appropriations
Subcommittee on Agriculture & FDA
2407 Rayburn House Office Building
Washington, DC 20515

Dear Chairman Frelinghuysen, Ranking Member Lowey, Chairman Cole and Ranking Member DeLauro, and Chairman Aderholt and Ranking Member Bishop:

We thank you for recognizing and responding decisively in the Fiscal Year 2017 (FY17) appropriations bills to address the challenges of Alzheimer's disease and other forms of dementia (including vascular, Lewy body dementia and frontotemporal degeneration). We support your efforts to cement the planned funding for dementia with enactment of a FY17 budget before the continuing resolution expires in April. 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.

As you work to construct Fiscal Year 2018 (FY18) appropriations bills – which we hope will be based on the anticipated FY17 levels being achieved – we urge that you ensure continued momentum toward the National Alzheimer's Plan goals and your own commitment to advancing science, care, and support. **Specifically, we request that the FY18 appropriations bills include at least the following minimum increases over the anticipated FY17 funding levels:**

- **\$414 million for NIH research for Alzheimer’s disease and other forms of dementia** – consistent with [NIH’s Professional Judgment Budget](#) -- resulting in an NIH-wide dementia research budget of at least \$1.8 billion in FY18.
- **\$500 million for aging research across the NIH, in addition to the funding for dementia-specific research.** This increase will ensure that the NIH and NIA have the resources they need, not only to address dementia specifically, but also the many other age-related chronic diseases that affect people with dementia.
- **\$2 billion for the NIH, in addition to funds included in the 21st Century Cures Act for targeted initiatives.**
- **\$78 million for the FDA, in addition to funds included in the 21st Century Cures Act for targeted initiatives.**
- **\$35 million for dementia care and services programs**, including \$10 million for the CDC’s Healthy Brain Initiative, \$15 million for the Administration for Community Living (ACL) Alzheimer’s Disease Initiative to increase public awareness and expand access to home-and-community-based dementia supportive services, \$5 million to fund Alzheimer’s demonstration grants to the states to develop improved models of care for people with dementia, and \$5 million for Department of Justice’s Missing Alzheimer’s Disease Patient Alert Program.

If not already enacted into law through the FY17 appropriations process, we urge you to include in the FY18 appropriations bills:

- Language directing CMS to conduct a demonstration project of promising evidence-based caregiver support and counseling services intended to enable Medicare beneficiaries with Alzheimer’s disease and other forms of dementia to receive care in their homes for longer periods of time, thus delaying and limiting the use of more costly institutional care.
- Language directing CMS to integrate services across Medicare to ensure that beneficiaries diagnosed with Alzheimer’s disease and other forms of dementia, and their families, receive access to information about the likely trajectory of their disease, care planning, and related supports and services such as palliative care.

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 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.^{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 research into Alzheimer's disease and other forms of dementia 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 FY17 and FY18, 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, the millions of Americans currently living with dementia deserve strengthened commitments to programs to protect and enhance their quality of life. New funding is essential to sustain core Older Americans Act services at the Administration of Community Living and to develop and disseminate services instrumental to achieve 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 other forms of dementia. 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,

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| Abe's Garden | David M. Bass, PhD (Benjamin Rose Institute on Aging*) |
| ActivistsAgainstAlzheimer's | Beating Alzheimer's by Embracing Science |
| African American Network Against Alzheimer's | Benjamin Rose Institute on Aging |
| AgeneBio | Biogen |
| Aging and Memory Disorder Programs, Howard University | Soo Borson MD (University of Washington Schools of Medicine and Nursing*) |
| Paul S. Aisen, MD (Keck School of Medicine of USC, Alzheimer's Therapeutic Research Institute*) | James Brewer, M.D., Ph.D. (UC San Diego and Alzheimer's Disease Cooperative Study*) |
| Alliance for Aging Research | BrightFocus Alzheimer's Disease Research |
| Alliance for Patient Access | Christopher M. Callahan, MD (Indiana University Center for Aging Research*) |
| Alzheimer's & Dementia Alliance of Wisconsin | Caregiver Action Network |
| Alzheimer's Disease Resource Center | CaringKind |
| Alzheimer's Foundation of America | Center for BrainHealth at The University of Texas at Dallas |
| Alzheimer's Greater Los Angeles | Center for Elder Care and Advanced Illness, Altarum Institute |
| Alzheimer's Mississippi | Center to Advance Palliative Care |
| Alzheimer's New Jersey | Sandra Bond Chapman, PhD (Center for BrainHealth at The University of Texas at Dallas*) |
| Alzheimer's Orange County | ClergyAgainstAlzheimer's |
| Alzheimer's San Diego | Cleveland Clinic Foundation |
| Alzheimer's Tennessee | Coalition Against Major Diseases |
| Alzheimer's Texas | Cognition Therapeutics |
| American Academy of Neurology | CorTechs Labs |
| American Association for Geriatric Psychiatry | Suzanne Craft, PhD (Wake Forest School of Medicine*) |
| American Federation for Aging Research | Critical Path Institute |
| American Geriatrics Society | Jeffrey Cummings, MD, ScD (Cleveland Clinic Lou Ruvo Center for Brain Health*) |
| American Medical Women's Association | Cure Alzheimer's Fund |
| ARGENTUM Expanding Senior Living | |
| Association of Population Centers | |
| Avanir | |
| Laura D. Baker, PhD (Wake Forest School of Medicine*) | |
| Banner Alzheimer's Institute | |

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| Darrell K. Royal Fund for Alzheimer's Research | Katherine S. Judge, PhD (Cleveland State University*) |
| Dementia Alliance International | Keck School of Medicine of USC, Alzheimer's Therapeutic Research Institute |
| Department of Neurology, Washington University School of Medicine | Keep Memory Alive |
| Gary Epstein-Lubow, MD (Alpert Medical School of Brown University*) | Diana R Kerwin, MD (Texas Alzheimer's and Memory Disorders*) |
| Faith United Against Alzheimer's Coalition | Walter A. Kukull, PhD (School of Public Health, University of Washington*) |
| Friends of the National Institute on Aging (FoNIA) | LatinosAgainstAlzheimer's |
| Sam Gandy, MD, PhD (Icahn School of Medicine at Mount Sinai*) | Latino Alzheimer's and Memory Disorders Alliance |
| Joseph E. Gaugler, Ph.D. (School of Nursing, Center on Aging, University of Minnesota*) | LeadingAge |
| General Electric | Lewy Body Dementia Association |
| Daniel R. George, Ph.D, M.Sc (Penn State College of Medicine*) | LinkedSenior, Inc. |
| Georgetown University Medical Center Memory Disorders Program | Lundbeck |
| Georgia Institute on Aging | Kostas Lyketsos, M.D., M.H.S. (Johns Hopkins Memory and Alzheimer's Treatment Center*) |
| Gerontological Society of America | David G. Morgan, PhD (USF Health Byrd Alzheimer's Institute*) |
| Laura N. Gitlin, PhD (Johns Hopkins School of Medicine*) | Mount Sinai Center for Cognitive Health |
| Lisa P. Gwyther, MSW, LCSW (Duke University Medical Center*) | National Asian Pacific Center on Aging |
| David Holtzman, MD (Washington University School of Medicine, Department of Neurology*) | National Association of Activity Professionals |
| Home Instead Senior Care | National Association of Area Agencies on Aging |
| Indiana University Center for Aging Research | National Association of Chronic Disease Directors |
| Janssen R&D | National Association of States United for Aging and Disabilities |
| Kathy Jedrziwski, PhD (University of Pennsylvania*) | National Certification Council for Activity Professionals |
| Johns Hopkins Memory and Alzheimer's Treatment Center | National Coalition for Hospice and Palliative Care |
| Johns Hopkins School of Nursing Center for Innovative Care in Aging | National Committee to Preserve Social Security and Medicare |
| | National Hispanic Council On Aging (NHCOA) |

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| National Task Group on Intellectual Disabilities and Dementia Practices | Rudolph Tanzi, PhD (Department of Neurology, MGH/Harvard Medical School*) |
| Neurocern | The Association for Frontotemporal Degeneration |
| Neurotechnology Industry Organization | The Evangelical Lutheran Good Samaritan Society |
| New York Academy of Sciences | The Youth Movement Against Alzheimer's |
| NFL Neurological Center | R. Scott Turner, MD, PhD (Georgetown University Memory Disorders Program*) |
| NYU Alzheimer's Disease Center | UsAgainstAlzheimer's, LEAD Coalition co-convener |
| NYU Langone Center on Cognitive Neurology | USF Health Byrd Alzheimer's Institute |
| NYU Langone Medical Center | Visiting Nurse Associations of America |
| Noah Homes | Volunteers of America, LEAD Coalition co-convener |
| Thomas O. Obisesan, MD, MPH (Howard University Hospital*) | Michael W. Weiner, MD (University of California San Francisco*) |
| Pat Summitt Foundation | Nancy Wilson, MA LCSW (Baylor College of Medicine*) |
| Piramal Imaging S.A. | Wisconsin Alzheimer's Institute |
| Planetree | WomenAgainstAlzheimer's |
| Population Association of America | |
| Prevent Alzheimer's Disease 2020 | |
| Eric Reiman, MD (Banner Alzheimer's Institute*) | |
| ResearchersAgainstAlzheimer's | |
| Stephen Salloway, M.D., M.S. (The Warren Alpert Medical School of Brown University*) | |

** 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>

ⁱⁱⁱ <http://annals.org/article.aspx?articleid=2466364#>

^{iv} <http://aspe.hhs.gov/daltcp/napa/NatlPlan2014.pdf>

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

^{vi} <http://www.neurology.org/content/early/2014/03/05/WNL.0000000000000240>

^{vii} <http://www.alz.org/trajectory>

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- viii <http://aspe.hhs.gov/daltcp/napa/NatlPlan.pdf>
- ix <http://aspe.hhs.gov/daltcp/napa/012615/Mtg15-Slides4.pdf>
- x <http://www.nia.nih.gov/alzheimers/publication/2012-2013-alzheimers-disease-progress-report/genetics-alzheimers-disease>
- xi http://www.alz.org/downloads/facts_figures_2014.pdf
- xii http://www.usagainstalzheimers.org/sites/default/files/USA2_AAN_CostsReport.pdf
- xiii <http://www.nhcoa.org/wp-content/uploads/2013/05/NHCOA-Alzheimers-Executive-Summary.pdf> and http://www.usagainstalzheimers.org/sites/all/themes/alzheimers_networks/files/LatinosAgainstAlzheimers_Issue_Brief.pdf
- xiv http://aadmd.org/sites/default/files/NTG_Thinker_Report.pdf
- xv <http://www.nia.nih.gov/alzheimers/publication/2012-2013-alzheimers-disease-progress-report/advancing-discovery-alzheimers#priorities>
- xvi <https://www.nia.nih.gov/about/budget/2016/fiscal-year-2017-budget>
- xvii <http://aspe.hhs.gov/daltcp/napa/NatlPlan2014.pdf>
- xviii <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, 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.