



November 11, 2016

The Honorable Thad Cochran  
Chairman  
Committee on Appropriations  
S-128 The Capitol  
Washington, DC 25010

The Honorable Barbara Mikulski  
Vice Chairwoman  
Committee on Appropriations  
S-128 The Capitol  
Washington, DC 20510

The Honorable Roy Blunt  
Chairman  
Committee on Appropriations  
Subcommittee on Labor, HHS & Education  
135 Dirksen Senate Office Building  
Washington, D.C. 20510

The Honorable Patty Murray  
Ranking Member  
Committee on Appropriations  
Subcommittee on Labor, HHS & Education  
156 Dirksen Senate Office Building  
Washington, D.C. 20510

The Honorable Jerry Moran  
Chairman  
Committee on Appropriations  
Subcommittee on Agriculture & FDA  
129 Dirksen Senate Office Building  
Washington, DC 20510

The Honorable Jeff Merkley  
Ranking Member  
Committee on Appropriations  
Subcommittee on Agriculture & FDA  
129 Dirksen Senate Office Building  
Washington, DC 20510

Dear Chairman Cochran, Vice Chairwoman Mikulski, Chairman Blunt and Ranking Member Murray and Chairman Moran and Ranking Member Merkley:

We thank you for recognizing and responding decisively in the Fiscal Year 2017 appropriations bills to the challenges of Alzheimer's disease and other forms of dementia (including vascular, Lewy body dementia and frontotemporal degeneration). 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 finalize the Fiscal Year 2017 spending bills during the post-election session of Congress, we urge that you ensure the final agreement continues to reflect your commitment to advancing the science, care, and support. **Specifically, we request that the final legislation include:**

- **A minimum increase of \$400 million over the FY 16 enacted level in NIH research for Alzheimer's disease and other forms of dementia**, resulting in an NIH-wide dementia research budget of about \$1.336 billion in FY 2017.

- **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 at least \$2 billion over the FY 16 enacted level for the NIH.**
- **A minimum increase of at least \$120 million over the FY 16 enacted level for the FDA.**
- **A minimum increase of \$35 million over the FY 2016 enacted levels 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.
- Language to direct 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 be cared for in their homes for longer periods of time, thus delaying and limiting the use of more costly institutional care.
- Statutory language to establish a Medicare benefit 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.

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.<sup>i</sup> 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.<sup>ii</sup> 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.<sup>iii</sup> Today, more than five million Americans<sup>iv</sup> have dementia at an annual cost to our economy exceeding \$200 billion.<sup>v</sup> 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.<sup>vi</sup> 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.<sup>vii</sup> 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.<sup>viii</sup>

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.<sup>ix</sup> 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;<sup>x</sup> address health disparities among women,<sup>xi</sup> African Americans,<sup>xii</sup> Hispanics,<sup>xiii</sup> and persons with intellectual disabilities;<sup>xiv</sup> and pursue cutting-edge trials aimed at preventing or substantially slowing disease progression by administering treatments much earlier in the disease process.<sup>xv</sup> In FY 2017, the NIA plans to increase its research focus on dementia epidemiology, health disparities, and caregiving.<sup>xvi</sup>

As urgently as resources are needed to enable scientific breakthroughs, millions of Americans already 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 and develop and disseminate evidence-based services instrumental to achieving the national plan's goals to enhance care quality, efficiency and expand supports.<sup>xvii</sup> 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),<sup>xviii</sup> [ikremer@leadcoalition.org](mailto:ikremer@leadcoalition.org) or (571) 383-9916, with questions or for additional information.

Sincerely,

Abe's Garden  
ActivistsAgainstAlzheimer's  
African American Network  
Against Alzheimer's  
Ageless Alliance  
AgeneBio

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Alliance for Patient Access  
Alzheimer's & Dementia Alliance  
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Alzheimer's Drug Discovery Foundation  
Alzheimer's Foundation of America  
Alzheimer's Greater Los Angeles  
Alzheimer's Mississippi  
Alzheimers North Carolina  
Alzheimer's Orange County  
Alzheimer's San Diego  
Alzheimer's Tennessee  
American Academy of Neurology  
American Association for Geriatric  
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American Federation for Aging  
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American Medical Women's Association  
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CurePSP  
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 National Association of Activity  
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 National Association of Chronic Disease  
 Directors  
 National Association of States United for  
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 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  
 Neurocern  
 Neurotechnology Industry Organization  
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 Pat Summitt Foundation  
 Piramal Imaging S.A.  
 Planetree  
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*\* Affiliations of individual researchers are for identification purposes only and do not necessarily represent the endorsement of affiliated institutions.*

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

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

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

<sup>iv</sup> <http://aspe.hhs.gov/daltcp/napa/NatlPlan2014.pdf>

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

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

<sup>vii</sup> <http://www.alz.org/trajectory>

<sup>viii</sup> <http://aspe.hhs.gov/daltcp/napa/NatlPlan.pdf>

<sup>ix</sup> <http://aspe.hhs.gov/daltcp/napa/012615/Mtg15-Slides4.pdf>

<sup>x</sup> <http://www.nia.nih.gov/alzheimers/publication/2012-2013-alzheimers-disease-progress-report/genetics-alzheimers-disease>

<sup>xi</sup> [http://www.alz.org/downloads/facts\\_figures\\_2014.pdf](http://www.alz.org/downloads/facts_figures_2014.pdf)

<sup>xii</sup> [http://www.usagainstalzheimers.org/sites/default/files/USA2\\_AAN\\_CostsReport.pdf](http://www.usagainstalzheimers.org/sites/default/files/USA2_AAN_CostsReport.pdf)

<sup>xiii</sup> <http://www.nhcoa.org/wp-content/uploads/2013/05/NHCOA-Alzheimers-Executive-Summary.pdf> and

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[http://www.usagainstalzheimers.org/sites/all/themes/alzheimers\\_networks/files/LatinosAgainstAlzheimers\\_Issue\\_Brief.pdf](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](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.