



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

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Beating Alzheimer's by Embracing
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Cure Alzheimer's Fund

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Keep Memory Alive

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Latino Alzheimer's and Memory
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Lewy Body Dementia Association

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National Alliance for Caregiving

National Asian Pacific Center on Aging

National Association of Nutrition and
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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
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 Piramal Imaging S.A.
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 The Evangelical Lutheran
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** Affiliations of individual researchers are for identification purposes only and do not necessarily represent the endorsement of the affiliated institution.*

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- 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>
- ^{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 Alzheimer's disease and related dementias -- including vascular, Lewy body or frontotemporal dementia -- 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.