



November 11, 2016

The Honorable Hal Rogers
Chairman
Committee on Appropriations
H-305 The Capitol
Washington, DC 20515

The Honorable Nita Lowey
Ranking Member
Committee on Appropriations
2365 Rayburn 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
2413 Rayburn House Office Building
Washington, DC 20515

The Honorable Robert Aderholt
Chairman
Committee on Appropriations
Subcommittee on Agriculture & FDA
2362-A Rayburn House Office Building
Washington, DC 20515

The Honorable Sam Farr
Ranking Member
Committee on Appropriations
Subcommittee on Agriculture and FDA
1126 Longworth House Office Building
Washington, DC 20515

Dear Chairmen Rogers, Cole, and Aderholt, and Ranking Members Lowey, DeLauro, and Farr:

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.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 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 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.^{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,

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

Aging and Memory Disorder Programs,
Howard University
Paul S. Aisen, MD (Keck School of
Medicine of USC, Alzheimer's
Therapeutic Research Institute*)
Allergan
Alliance for Aging Research

Alliance for Patient Access	Caregiver Action Network
Alzheimer's & Dementia Alliance of Wisconsin	CaringKind
Alzheimer's Drug Discovery Foundation	Center for BrainHealth at The University of Texas at Dallas
Alzheimer's Foundation of America	Center for Elder Care and Advanced Illness, Altarum Institute
Alzheimer's Greater Los Angeles	Center to Advance Palliative Care
Alzheimer's Mississippi	Sandra Bond Chapman, PhD (Center for BrainHealth at The University of Texas at Dallas*)
Alzheimers North Carolina	ClergyAgainstAlzheimer's
Alzheimer's Orange County	Cleveland Clinic Foundation
Alzheimer's San Diego	Coalition Against Major Diseases
Alzheimer's Tennessee	Cognition Therapeutics
American Academy of Neurology	CorTechs Labs
American Association for Geriatric Psychiatry	Jeffrey Cummings, MD, ScD (Cleveland Clinic Lou Ruvo Center for Brain Health*)
American Federation for Aging Research	Cure Alzheimer's Fund
American Geriatrics Society	CurePSP
American Medical Women's Association	Darrell K. Royal Fund for Alzheimer's Research
ARGENTUM Expanding Senior Living	Dementia Alliance International
Association of Population Centers	Dementia Friendly America
Laura D. Baker, PhD (Wake Forest School of Medicine*)	Department of Neurology, Washington University School of Medicine
Banner Alzheimer's Institute	Gary Epstein-Lubow, MD (Alpert Medical School of Brown University*)
David M. Bass, PhD (Benjamin Rose Institute on Aging*)	Faith United Against Alzheimer's Coalition
Beating Alzheimer's by Embracing Science	Friends of the National Institute on Aging (FoNIA)
Benjamin Rose Institute on Aging	Fujirebio
Biogen	Joseph E. Gaugler, Ph.D. (School of Nursing, Center on Aging, University of Minnesota*)
B'nai B'rith International	General Electric
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	

Georgetown University Medical Center
Memory Disorders Program

Georgia Institute on Aging

Gerontological Society of America

Laura N. Gitlin, PhD (Johns Hopkins
School of Medicine*)

Lisa P. Gwyther, MSW, LCSW
(Duke University Medical Center*)

Hadassah, The Women's Zionist
Organization of America, Inc.

David Holtzman, MD
(Washington University School of
Medicine, Department of Neurology*)

Home Instead Senior Care

Janssen R&D

Kathy Jedrzejewski, PhD (University of
Pennsylvania*)

Johns Hopkins Memory and Alzheimer's
Treatment Center

Johns Hopkins School of Nursing Center
for Innovative Care in Aging

Katherine S. Judge, PhD (Cleveland
State University*)

Keck School of Medicine of USC,
Alzheimer's Therapeutic Research
Institute

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

LeadingAge

Lewy Body Dementia Association

LuMind Research Down
Syndrome Foundation

Lundbeck

Kostas Lyketsos, M.D., M.H.S. (Johns
Hopkins Memory and Alzheimer's
Treatment Center*)

David G. Morgan, PhD (USF
Health Byrd Alzheimer's Institute*)

National Alliance for Caregiving

National Asian Pacific Center on Aging

National Association of Activity
Professionals

National Association of Chronic Disease
Directors

National Association of States United for
Aging and Disabilities

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

New York Academy of Sciences

NYU Langone Medical Center

Noah Homes

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

Presence Care Project

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*)
Second Wind Dreams, Inc./
Virtual Dementia Tour
Society for Women's Health Research
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
Michael W. Weiner, MD (University of
California San Francisco*)
WomenAgainstAlzheimer's

** 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>

^{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.