



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
Alzheimer's & Dementia Alliance
of Wisconsin
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
Psychiatry
American Federation for Aging
Research
American Geriatrics Society
American Medical Women's Association
ARGENTUM | Expanding Senior Living
Association of Population Centers
Laura D. Baker, PhD (Wake Forest
School of Medicine*)
Banner Alzheimer's Institute
David M. Bass, PhD (Benjamin Rose
Institute on Aging*)
Beating Alzheimer's by Embracing
Science
Benjamin Rose Institute on Aging
Biogen
B'nai B'rith International
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

Caregiver Action Network
CaringKind
Center for BrainHealth at The University
of Texas at Dallas
Center for Elder Care and Advanced
Illness, Altarum Institute
Center to Advance Palliative Care
Sandra Bond Chapman, PhD (Center for
BrainHealth at The University of Texas
at Dallas*)
ClergyAgainstAlzheimer's
Cleveland Clinic Foundation
Coalition Against Major Diseases
Cognition Therapeutics
CorTechs Labs
Jeffrey Cummings, MD, ScD (Cleveland
Clinic Lou Ruvo Center for Brain
Health*)
Cure Alzheimer's Fund
CurePSP
Darrell K. Royal Fund for
Alzheimer's Research
Dementia Alliance International
Dementia Friendly America
Department of Neurology, Washington
University School of Medicine
Gary Epstein-Lubow, MD
(Alpert Medical School of
Brown University*)
Faith United Against Alzheimer's
Coalition
Friends of the National Institute on
Aging (FoNIA)
Fujirebio
Joseph E. Gaugler, Ph.D. (School of
Nursing, Center on Aging, University
of Minnesota*)
General Electric

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 Jedrziwski, 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.