



November 18, 2015

The Honorable Thad Cochran
Chairman
Committee on Appropriations
United States Senate
S 128 The Capitol
Washington, DC 20510

The Honorable Barbara Mikulski
Ranking Member
Committee on Appropriations
United States Senate
S-146 A The Capitol
Washington, DC 20510

The Honorable Roy Blunt
Chairman
Committee on Appropriations
Subcommittee on Labor, HHS
and Education
131 Dirksen Senate Office Building
Washington, DC 20510

The Honorable Patty Murray
Ranking Member
Committee on Appropriations
Subcommittee on Labor, HHS
and Education
131 Dirksen Senate Office Building
Washington, DC 20510

The Honorable Jerry Moran
Chairman
Committee on Appropriations
Subcommittee on Agriculture, Rural
Development, Food and Drug
Administration
521 Dirksen Senate Office Building
Washington, DC 20510

The Honorable Jeff Merkley
Ranking Member
Committee on Appropriations
Subcommittee on Agriculture, Rural
Development, and Food and Drug
Administration
313 Hart Senate Office Building
Washington, DC 20510

Via electronic delivery

Dear Chairmen Cochran, Blunt, and Moran, and Ranking Members Mikulski, Murray and Merkley:

We thank you and your Senate colleagues for responding decisively in the FY 2016 Labor, Health and Human Services, Education and Related Agencies Appropriations Act to our earlier calls for a robust increase in funding for NIH's research on Alzheimer's disease and other causes of dementia (including vascular, Lewy body and frontotemporal dementia).ⁱ If the Senate Appropriations Committee's plan for a \$350 million boost in FY 2016 becomes law, overall NIH investments in Alzheimer's and dementia research are estimated to reach \$936 million. That would be essential

and remarkable progress toward the \$2 billion in annual U.S. federal research funding committed to Alzheimer's disease and dementia research recommended by the scientific community and embraced by the non-federal members of the Advisory Council on Alzheimer's Research, Care, and Services that provides recommendations to the Secretary of Health and Human Resources for the National Plan to Address Alzheimer's Disease. But this vital progress will occur only if there is a full year appropriations agreement enacted into law. **Therefore, we urge the Senate to ensure that the FY2016 appropriations agreement is passed without further delay and that the final agreement includes the full \$350 million in Alzheimer's disease and dementia research funding approved by the Senate Appropriations Committee.**

For all its vital work, NIH cannot address the full spectrum of the dementia crisis by itself. For dementia prevention, treatment and cures to reach people in need, there must be robust resources for other federal agencies including the Food and Drug Administration and the Centers for Disease Control and Prevention. Until these scientific breakthroughs are achieved, meeting the urgent needs of people already living with dementia and their caregivers must be a national priority. It is imperative that significantly more resources are provided for programs serving people with dementia and caregivers through the Older Americans Act, the Administration for Community Living, the Health Resources and Services Administration, the Centers for Medicare and Medicaid Services, the Department of Veterans Affairs, and the Department of Justice. **Therefore, we urge the Senate to ensure that the recently raised budget caps are used to include in the FY 2016 appropriations agreement increased funding for the full range of dementia research and dementia service programs.**

There are few more compelling or complex issues to confront our aging society than Alzheimer's disease and other causes of dementia, now and over the coming decades. These conditions impose enormous costs to our nation's health and prosperity, costs that are skyrocketing.ⁱⁱ Today, more than five million Americansⁱⁱⁱ have dementia at an annual cost to our economy exceeding \$200 billion.^{iv} 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.^v If the current trajectory of the disease persists, at least 13 million Americans will have dementia in 2050 and total costs of care are projected to exceed \$1 trillion annually (in inflation adjusted 2014 dollars).^{vi} 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 Alzheimer's disease and other causes of 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 will help America prevent this

catastrophe and move us closer to achieving our national goal of preventing and effectively treating Alzheimer's disease and other causes of dementia by 2025.^{vii}

Due to leadership and direction from Congress, HHS continues to increase prioritization of Alzheimer's disease and other causes of dementia. Congress and the National Institutes of Health (NIH) have moved mountains to create additional resources, public-private partnerships, and a culture of urgency. Across the NIH, institutes are supporting promising dementia research to: understand genetic risk factors and identify biomarkers for screening susceptible people (including adults with Down syndrome);^{viii} address health disparities among women,^{ix} African Americans,^x Hispanics,^{xi} and persons with intellectual disabilities;^{xii} create a multi-site research consortium to test new treatments for frontotemporal lobar degeneration (FTLD);^{xiii} and pursue cutting-edge trials aimed at preventing or substantially slowing disease progression by administering treatments much earlier in the disease process.^{xiv}

As urgently as resources are needed to enable scientific breakthroughs, millions of Americans already living with dementia – and their families – deserve equal commitments to services and programs to protect and enhance their quality of life. New funding is essential to sustain core Older Americans Act services, and to develop and disseminate evidence-based services instrumental to achieving the national plan's goals to enhance care quality, efficiency and expand supports.^{xv} 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 causes of dementia. Please contact Ian Kremer, executive director of Leaders Engaged on Alzheimer's Disease (the LEAD Coalition),^{xvi} ikremer@leadcoalition.org or (571) 383-9916, with questions or for additional information.

Sincerely,

Academy of Radiology Research

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	Center for Elder Care and Advanced Illness, Altarum Institute
Alzheimer's Foundation of America, LEAD Coalition co-convenor	Center for Alzheimer Research and Treatment, Harvard Medical School
Alzheimers North Carolina	Center for BrainHealth at The University of Texas at Dallas
Alzheimer's Tennessee	Sandra Bond Chapman, PhD (Center for BrainHealth at The University of Texas at Dallas*)
AMDA – The Society for Post-Acute and Long-Term Care Medicine	ClergyAgainstAlzheimer's
American Academy of Neurology	Cleveland Clinic Foundation
American Association for Geriatric Psychiatry	Coalition for Imaging and Bioengineering Research
American Association for Long Term Care Nursing	Cognition Therapeutics
American Federation for Aging Research (AFAR)	CorTechs Labs
American Geriatrics Society	Jeffrey Cummings, MD, ScD (Cleveland Clinic Lou Ruvo Center for Brain Health*)
Argentum	Cure Alzheimer's Fund
Laura D. Baker, PhD (Wake Forest School of Medicine*)	Darrell K. Royal Fund for Alzheimer's Research
Banner Alzheimer's Institute	Dementia Alliance International
Beating Alzheimer's by Embracing Science	Department of Neurology, Washington University School of Medicine
Blanchette Rockefeller Neurosciences Institute	Rachelle S. Doody, MD, PhD (Baylor College of Medicine*)
Soo Borson MD (University of Washington Schools of Medicine and Nursing*)	Gary Epstein-Lubow, MD (Alpert Medical School of Brown University*)
James Brewer, M.D., Ph.D. (UC San Diego and Alzheimer's Disease Cooperative Study*)	Fujirebio
BrightFocus Alzheimer's Disease Research	Sam Gandy, MD, PhD (Icahn School of Medicine at Mount Sinai*)
Christopher M. Callahan, MD (Indiana University Center for Aging Research*)	Joseph E. Gaugler, Ph.D. (School of Nursing, Center on Aging, University of Minnesota*)
Caregiver Action Network	Geoffrey Beene Foundation Alzheimer's Initiative

Georgetown University Medical Center Memory Disorders Program	National Committee to Preserve Social Security and Medicare
Georgia Institute on Aging	National Council for Behavioral Health
Gerontological Society of America	National Down Syndrome Society
Laura N. Gitlin, PhD (Johns Hopkins School of Medicine*)	National Hispanic Council On Aging (NHCOA)
Lisa P. Gwyther, MSW, LCSW (Duke University Medical Center*)	National Task Group on Intellectual Disabilities and Dementia Practices
David Holtzman, MD (Washington University School of Medicine, Department of Neurology*)	Neurocern
Home Instead Senior Care	Neurotechnology Industry Organization
Indiana University Center for Aging Research	New York Academy of Sciences
Janssen R&D	NFL Neurological Center
Johns Hopkins School of Nursing Center for Innovative Care in Aging	Thomas O. Obisesan, MD, MPH (Howard University Hospital*)
Katherine S. Judge PhD (Cleveland State University*)	OWL-The Voice of Women 40+
Keep Memory Alive	Pat Summitt Foundation
Walter A. Kukull, PhD (School of Public Health, University of Washington*)	Planetree
LatinosAgainstAlzheimer's	Presence Care Project
LeadingAge	Prevent Alzheimer's Disease 2020
Lewy Body Dementia Association	Eric Reiman, MD (Banner Alzheimer's Institute*)
Linked Senior, Inc	Research!America
LuMind Research Down Syndrome Foundation	ResearchersAgainstAlzheimer's
Mary Mittelman, DrPH (New York University Medical Center*)	Stephen Salloway, M.D., M.S. (The Warren Alpert Medical School of Brown University*)
David G. Morgan, PhD (USF Health Byrd Alzheimer's Institute*)	Second Wind Dreams, Inc./ Virtual Dementia Tour
Mount Sinai Center for Cognitive Health	Reisa A. Sperling, MD, MMSc (Center for Alzheimer Research and Treatment, Harvard Medical School*)
National Asian Pacific Center on Aging	Rudolph Tanzi, PhD (Department of Neurology, MGH/Harvard Medical School*)
National Certification Council for Activity Professionals	

The Association for Frontotemporal
Degeneration

The Eden Alternative

The Evangelical Lutheran
Good Samaritan Society

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

Michael W. Weiner, MD (University of
California San Francisco*)

Wisconsin Alzheimer's Institute

WomenAgainstAlzheimer's

** 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.leadcoalition.org/?wpfb_dl=154
- ⁱⁱ <http://www.nejm.org/doi/pdf/10.1056/NEJMsa1204629>
- ⁱⁱⁱ <http://aspe.hhs.gov/daltcp/napa/NatlPlan2014.pdf>
- ^{iv} <http://www.nejm.org/doi/pdf/10.1056/NEJMsa1204629>
- ^v <http://www.neurology.org/content/early/2014/03/05/WNL.0000000000000240>
- ^{vi} <http://www.alz.org/trajectory>
- ^{vii} <http://aspe.hhs.gov/daltcp/napa/NatlPlan.pdf>
- ^{viii} <http://www.nia.nih.gov/alzheimers/publication/2012-2013-alzheimers-disease-progress-report/genetics-alzheimers-disease>
- ^{ix} http://www.alz.org/downloads/facts_figures_2014.pdf
- ^x http://www.usagainstalzheimers.org/sites/default/files/USA2_AAN_CostsReport.pdf
- ^{xi} <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
- ^{xii} http://aadmd.org/sites/default/files/NTG_Thinker_Report.pdf
- ^{xiii} <https://www.nia.nih.gov/alzheimers/clinical-trials/advancing-research-and-treatment-frontotemporal-lobar-degeneration-artfl>
- ^{xiv} <http://www.nia.nih.gov/alzheimers/publication/2012-2013-alzheimers-disease-progress-report/advancing-discovery-alzheimers#priorities>
- ^{xv} <http://aspe.hhs.gov/daltcp/napa/NatlPlan2014.pdf>
- ^{xvi} <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 other causes of dementia -- 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.