



March 12, 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 & 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

Dear Chairmen Cochran and Blunt and Ranking Members Mikulski and Murray:

We thank Congress for recognizing and responding decisively in FY 2015 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.

As you assemble the FY 2016 Labor, Health and Human Services, Education and Related Agencies Appropriations Act, we urge that you include:

- **At least \$32 billion in funding for the National Institutes of Health (NIH) overall, the amount recommend by the Ad Hoc Group for Medical Research;**
- **An increase of at least \$500 million for the National Institute on Aging from the final FY 15 enacted level;**
- **An aggressive ramp-up to the \$2 billion level for Alzheimer's disease and related dementias research at the NIH, ideally by doubling the amount available for this research over the FY 2015 level and, at a minimum, providing a year-over-year increase of at least \$200 million; and**
- **An increase of at least \$9 million for the Alzheimer's Disease Demonstration Grants and \$11 million for the Alzheimer's Disease Initiative, along with the**

funding increases for related care and support programs at the Department of Health and Human Services.

There are few more compelling or complex issues to confront our aging society than Alzheimer's disease and related dementias, now and over the coming decades. These conditions impose enormous costs to our nation's health and prosperity, costs that are skyrocketing.ⁱ Today, more than five million Americansⁱⁱ have dementia at an annual cost to our economy exceeding \$200 billion.ⁱⁱⁱ 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.^{iv} 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 (inflation adjusted 2014 dollars) \$1 trillion annually.^v 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 related dementias -- 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 Alzheimer's disease and related dementias by 2025.^{vi}

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.^{vii} The Food and Drug Administration is encouraging new research avenues and clarifying regulatory approval pathways. Your committee 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 Alzheimer's disease and related dementias research to: understand genetic risk factors;^{viii} address health disparities among women,^{ix} African Americans,^x Hispanics,^{xi} and persons with intellectual disabilities;^{xii} and pursue cutting-edge trials aimed at preventing or substantially slowing disease progression by administering treatments much earlier in the disease process.^{xiii}

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.^{xiv} 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),^{xv} ikremer@leadcoalition.org or (571) 383-9916, with questions or for additional information.

Sincerely,

Abe's Garden

Academy of Radiology Research

ActivistsAgainstAlzheimer's

ACT on Alzheimer's

African American Network Against
Alzheimer's

Alliance for Aging Research

Alliance for Patient Access

Alzheimer's & Dementia Alliance of
Wisconsin

Alzheimer's Drug Discovery Foundation

Alzheimer's Foundation of America, LEAD
Coalition co-convenor

Alzheimers North Carolina

Alzheimer's Tennessee

American Academy of Neurology

American Aging Association

American Association for Long Term Care
Nursing

American Federation for Aging Research
(AFAR)

American Geriatrics Society

Assisted Living Federation of America

Laura D. Baker, PhD (Wake Forest School
of Medicine*)

Beating Alzheimer's by Embracing Science

Biotechnology Industry Organization

Blanchette Rockefeller Neurosciences
Institute

Alice Bonner, PhD, RN (Northeastern
University Bouve' College of Health
Sciences*)

James Brewer, M.D., Ph.D. (UC San Diego
and Alzheimer's Disease Cooperative
Study*)

BrightFocus Alzheimer's Disease Research

Caregiver Action Network

Center for Alzheimer Research and
Treatment, Harvard Medical School

Center for BrainHealth at The University of
Texas at Dallas

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 for Imaging and Bioengineering
Research

Cognition Therapeutics

CorTechs Labs

Suzanne Craft, PhD (Wake Forest School of
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Jeffrey Cummings, MD, ScD (Cleveland
Clinic Lou Ruvo Center for Brain Health*)

Cure Alzheimer's Fund

Darrell K. Royal Fund for Alzheimer's
Research

Dementia Alliance International

Department of Neurology, Washington
University School of Medicine

Rachelle S. Doody, MD, PhD (Baylor
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Geoffrey Beene Foundation Alzheimer's
Initiative

Georgetown University Medical Center
Memory Disorders Program

Gerontological Society of America

Global Coalition on Aging

Lisa P. Gwyther, MSW, LCSW (Duke
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David Holtzman, MD (Washington
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Department of Neurology*)

Home Instead Senior Care

Iona Senior Services

Keep Memory Alive

Diana R Kerwin, MD (Texas Alzheimer's
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Walter A. Kukull, PhD (School of Public
Health, University of Washington*)

LatinosAgainstAlzheimer's

Latino Alzheimer's and Memory Disorders
Alliance

League of United Latin American Citizens

Lewy Body Dementia Association

Linked Senior, Inc

LuMind Research Down Syndrome
Foundation

Mary Mittelman, DrPH (New York University
Medical Center*)

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

National Alliance for Caregiving

National Association of Activity
Professionals

National Association of Social Workers
(NASW)

National Association of States United for
Aging and Disabilities

National Caucus and Center on Black Aged,
Inc. (NCBA)

National Certification Council for Activity
Professionals

National Committee to Preserve Social
Security and Medicare

National Down Syndrome Society

National Hispanic Council On Aging

National Task Group on Intellectual
Disabilities and Dementia Practices

Neurocern

Neurotechnology Industry Organization

NYU Alzheimer's Disease Center

NYU Langone Center on Cognitive
Neurology

OWL-The Voice of Women 40+

Pat Summitt Foundation

Piramal Imaging S.A.

Presence Care Project

Peter Reed, PhD (Sanford Center for Aging,
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ResearchersAgainstAlzheimer's

Sage Bionetworks

Stephen Salloway, M.D., M.S. (The Warren
Alpert Medical School of Brown
University*)

Reisa A. Sperling, MD, MMSc (Center for
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Harvard Medical School*)

Rudolph Tanzi, PhD (Department of
Neurology, MGH/Harvard Medical
School*)

Taos Health Systems

THE GREEN HOUSE® Project

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*)

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.nejm.org/doi/pdf/10.1056/NEJMsa1204629>
- ⁱⁱ <http://aspe.hhs.gov/daltcp/napa/NatlPlan2014.pdf>
- ⁱⁱⁱ <http://www.nejm.org/doi/pdf/10.1056/NEJMsa1204629>
- ^{iv} <http://www.neurology.org/content/early/2014/03/05/WNL.0000000000000240>
- ^v <http://www.alz.org/trajectory>
- ^{vi} <http://aspe.hhs.gov/daltcp/napa/NatlPlan.pdf>
- ^{vii} <http://aspe.hhs.gov/daltcp/napa/012615/Mtg15-Slides4.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} <http://www.nia.nih.gov/alzheimers/publication/2012-2013-alzheimers-disease-progress-report/advancing-discovery-alzheimers#priorities>
- ^{xiv} <http://aspe.hhs.gov/daltcp/napa/NatlPlan2014.pdf>
- ^{xv} <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.