



April 3, 2014

The Honorable Barbara A. Mikulski
Chairman
Committee on Appropriations
United States Senate
S. 128 The Capitol
Washington, DC 20510

The Honorable Richard Shelby
Ranking Member
Committee on Appropriations
United States Senate
S. 128 The Capitol
Washington, DC 20510

The Honorable Tom Harkin
Chairman
Committee on Appropriations
Subcommittee on Labor, HHS & Education
131 Dirksen Senate Office Building
Washington, DC 20510

The Honorable Jerry Moran
Ranking Member
Committee on Appropriations
Subcommittee on Labor, HHS &
Education
156 Dirksen Senate Office Building
Washington, DC 20510

Dear Chairwoman Mikulski, Chairman Harkin, Ranking Member Shelby and Ranking Member Moran:

We thank Congress for recognizing and responding decisively in the FY 2014 Omnibus Budget to the challenges of Alzheimer's disease and related disorders including vascular, Lewy body or 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. Doing so is a national priority, an economic and budgetary necessity, a health and moral imperative.

As you assemble the Fiscal Year 2015 Labor, Health and Human Services, Education and Related Agencies Appropriations Act, **we urge that you include \$32 billion for the National Institutes of Health (NIH). Of this amount, we request that you provide sufficient funding to support at least \$200 million in additional Alzheimer's disease and related disorders research to build upon the gains of recent years. We request also that you increase funding at the Administration for Community Living (ACL) by \$25 million for important caregiving and patient support programs.**

We support the recommendation of leading scientists and of the Advisory Council on Alzheimer's Research, Care and Services that Congress and NIH ramp up Alzheimer's disease and related disorders research investments to a minimum of \$2 billion annually (FY 2014 investments are projected to remain below \$580 million). A minimum \$200 million increase in FY 2015 would be a bold and strategically imperative next step forward in addressing what now appears to be the third leading cause of death among all Americans.ⁱ

Alzheimer's disease and related disorders currently impose enormous costs to our nation's health and prosperity, costs that are skyrocketing.ⁱⁱ The choice before our nation is not whether to pay for these diseases but 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. Will we resolve to invest now in accelerated research and improved care, or will we surrender millions of deaths and trillions of dollars in healthcare costs because we acted too tentatively or too late?

Thanks to unanimous action by Congress, two years ago our nation adopted its first National Plan to Address Alzheimer's Disease.ⁱⁱⁱ To achieve the plan's first goal of preventing and treating Alzheimer's disease by 2025, the right and necessary next step is to include at least an additional \$200 million for Alzheimer's disease and related disorders research funding at the NIH above the estimated FY 2014 level. These dollars will support potentially groundbreaking research projects, particularly those aimed at better understanding the causes of Alzheimer's disease and related disorders and exploring ways to prevent or intervene at the earliest stages.

We also urge that you include at least \$25 million in new funding to support ACL's vital work to develop and disseminate evidence-based support services for Alzheimer's disease and related disorders patients and family caregivers. These programs are instrumental in achieving the plan's goals to enhance care quality, efficiency and expand supports. They 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, 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 and free from more costly institutional settings.

Thank you for considering our views and for your commitment to overcoming Alzheimer's disease and related disorders. Please contact Ian Kremer, the LEAD Coalition's executive director, at ikremer@leadcoalition.org or (571) 383-9916, with questions or for additional information.^{iv}

Sincerely,

Abe's Garden

Activists Against Alzheimer's Network

African American Network Against
Alzheimer's

Alliance for Aging Research

Alzheimers North Carolina

Alzheimer's & Dementia Alliance of
Wisconsin

Alzheimer's Drug Discovery Foundation

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

Alzheimer's Tennessee

AMDA-The Society for Post-Acute and
Long-Term Care Medicine

American Academy of Neurology

American Association for Geriatric
Psychiatry

American Association for Long Term
Care Nursing

American Geriatrics Society

Assisted Living Federation of America

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

Beating Alzheimer's by Embracing
Science

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

BrightFocus Foundation

Caregiver Action Network

Center for Alzheimer Research and
Treatment, Harvard Medical School

Cleveland Clinic Foundation

Cognition Therapeutics

CorTechs Labs

Critical Path Institute

Jeffrey Cummings, MD, ScD (Cleveland
Clinic Lou Ruvo Center for Brain
Health*)

Cure Alzheimer's Fund

Darrell K. Royal Fund for Alzheimer's
Research

Rachelle S. Doody, MD, PhD (Baylor
College of Medicine*)

Down Syndrome Research and
Treatment Foundation

Forest Laboratories

Georgetown University Medical Center
Memory Disorders Program

Gerontological Society of America

Global Coalition on Aging

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

Home Instead Senior Care

Inspire

Janssen Research & Development, LLC

Keep Memory Alive

Lewy Body Dementia Association

Linked Senior, Inc.

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

National Alliance for Caregiving

National Association of States United for
Aging and Disabilities

National Down Syndrome Society

National Hispanic Council on Aging

National Task Group on Intellectual
Disabilities and Dementia Practices

Neurotechnology Industry Organization

New York Academy of Sciences

NYU Alzheimer's Disease Center

NYU Langone Center on Cognitive
Neurology

OWL-The Voice of Midlife and Older
Women

Pat Summitt Foundation

Piramal Imaging

Project Lifesaver International

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|----------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Research!America | R. Scott Turner, MD, PhD (Georgetown University Memory Disorders Program*) |
| ResearchersAgainstAlzheimer's | |
| Sage Bionetworks | USAgainstAlzheimer's, LEAD Coalition co-convener |
| Stephen Salloway, M.D., M.S. (The Warren Alpert Medical School of Brown University*) | USF Health Byrd Alzheimer's Institute |
| Reisa A. Sperling, MD, MMSc (Center for Alzheimer Research and Treatment, Harvard Medical School*) | Volunteers of America |
| Taos Health Systems | Washington University in St. Louis Department of Neurology, the Knight Alzheimer's Disease Research Center, and the Hope Center for Neurological Disorders |
| The Association for Frontotemporal Degeneration | Wisconsin Alzheimer's Institute |
| | Women Against Alzheimer's |

** Affiliations of individual researchers are for identification purposes only and do not necessarily represent the endorsement of the affiliated institution.*

ⁱ <http://www.neurology.org/content/early/2014/03/05/WNL.0000000000000240>

ⁱⁱ <http://www.nejm.org/doi/pdf/10.1056/NEJMsa1204629>

ⁱⁱⁱ <http://aspe.hhs.gov/daltcp/napa/NatlPlan2013.shtml>

^{iv} [Leaders Engaged on Alzheimer's Disease](#) (LEAD) is a diverse and growing national coalition of 65 member organizations including patient advocacy and voluntary health non-profits, philanthropies and foundations, trade and professional associations, academic research and clinical institutions, and homecare, biotechnology and pharmaceutical companies. The LEAD Coalition works collaboratively to focus the nation's strategic attention on Alzheimer's disease and related disorders 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.