

May 16, 2013

The Honorable Hal Rogers Chairman Committee on Appropriations H-307 The Capitol Washington, DC 20515

The Honorable Jack Kingston Chairman Committee on Appropriations Subcommittee on Labor, HHS & Education 2358-B Rayburn House Office Building Washington, DC 20515

The Honorable Nita Lowey Ranking Member Committee on Appropriations 1016 Longworth House Office Building Washington, DC 20515

The Honorable Rosa DeLauro Ranking Member Committee on Appropriations Subcommittee on Labor, HHS & Education 1001 Longworth House Office Building Washington, DC 20515

VIA ELECTRONIC DELIVERY

Dear Chairman Rogers, Chairman Kingston, Ranking Member Lowey and Ranking Member DeLauro:

We applaud Congress and the Administration for recognizing and responding decisively to the challenges of Alzheimer's disease and related disorders. Equally important, 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.

We urge that as you assemble the Fiscal Year 2014 Labor, Health and Human Services, Education and Related Agencies Appropriations Act, you provide necessary resources for the commitment to prevent and treat Alzheimer's disease by 2025 and include within your bill a minimum of \$80 million in additional funding to support Alzheimer's disease and related disorders research conducted by the National Institutes of Health (NIH) along with at least \$20 million to support important caregiving and patient support initiatives managed by the Administration for Community Living (ACL), both of which were included in the Administration's budget proposal. Leaders Engaged on Alzheimer's Disease (LEAD) is a diverse and growing coalition of 58 member organizations including patient advocacy and voluntary health non-profits, philanthropies and foundations, trade and professional associations, academic research and clinical institutions, and 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 care and support, detection and diagnosis, and research leading to prevention, effective treatment and eventual cure. One or more participants may have a financial interest in the subjects addressed.

Alzheimer's disease and related disorders currently impose enormous costs to our nation's health and prosperity, costs that are skyrocketing. The choice before our nation is not whether we will address and pay for research and care supports but rather how we will do so: Will we resolve to innovate our way out of danger, as we have chosen to do when confronted with other similar challenges, or will we incur millions of deaths and hundreds of billions of dollars in annual healthcare costs because we acted too tentatively or too late?

This month marks the first anniversary since the issuance of the historic National Plan to Address Alzheimer's Disease. The plan's first goal is preventing and treating Alzheimer's disease by 2025. To achieve this, we must fulfill the strategy and actions, including the commitment of federal and non-federal funding for high-priority Alzheimer's disease and related disorders scientific research. The right and necessary next step is to include at least an additional \$80 million for Alzheimer's disease and related disorders research funding at the NIH above the estimated FY 13 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 intervene at the earliest stages.

We also urge that you include \$20 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 a treatment or cure comes to market, families rely on these programs to help their loved 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 <u>ikremer@leadcoalition.org</u> or (571) 383- 9916, with questions or for additional information.

Sincerely,

Abe's Garden

Alliance for Aging Research

Alzheimer's & Dementia Alliance of Wisconsin

Alzheimer's Drug Discovery Foundation

Alzheimer's Foundation of America

Alzheimers North Carolina

Alzheimer's Tennessee

AMDA – Dedicated to 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

Banner Alzheimer's Institute

Beating Alzheimer's by Embracing Science

BrightFocus Alzheimer's Disease Research

Caregiver Action Network

Center for Alzheimer Research and Treatment, Harvard Medical School

Cognition Therapeutics

Cortica Neurosciences, Inc.

Cure Alzheimer's Fund

Dr. Michael Devous Sr. (University of Texas Southwestern Medical Center*)

Rachelle S. Doody, MD, PhD (Baylor College of Medicine*) Friends of the National Institute on Aging

Geoffrey Beene Foundation -Alzheimer's Initiative

Georgetown University Medical Center Memory Disorders Program

Gerontological Society of America

Global Coalition on Aging

Howard University, Aging and Memory Disorder Programs

Inspire

Iona Senior Services

Latino Alzheimer's and Memory Disorders Alliance

LeadingAge

Linked Senior, Inc.

Memory Enhancement Center of America, Inc.

MyCare Personal Assistance

Dave Morgan, PhD (USF Health Byrd Alzheimer's Institute)

National Alliance for Caregiving

National Association of States United for Aging and Disabilities

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

National Down Syndrome Society

National Hispanic Council on Aging

Neurotechnology Industry Organization

New York Academy of Sciences

NYU Langone Comprehensive Center on Brain Aging/NYU Langone Silberstein Alzheimer's Institute NYU Alzheimer's Disease Center

Thomas O. Obisesan, MD, MPH (Howard University Hospital*)

Project Lifesaver International

RemeGenix, Inc.

- Research!America
- ResearchersAgainstAlzheimer's
- Stephen Salloway, M.D., M.S. (The Warren Alpert Medical School of Brown University*)
- The Association for Frontotemporal Degeneration

- R. Scott Turner, MD, PhD (Georgetown University Memory Disorders Program*)
- USAgainstAlzheimer's
- USF Health Byrd Alzheimer's Institute

Volunteers of America

Vradenburg Foundation

Washington University School of Medicine, Department of Neurology (St. Louis, Missouri)

WomenAgainstAlzheimer's

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