November 18, 2015

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

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

The Honorable Tom Cole
Chairman
Committee on Appropriations
Subcommittee on Labor, HHS and Education
2358-B Rayburn House Office Building
Washington, DC 20515

The Honorable Rosa DeLauro
Ranking Member
Committee on Appropriations
Subcommittee on Labor, HHS and Education
1016 Longworth House Office Building
Washington, DC 20515

The Honorable Robert Aderholt
Chairman
Committee on Appropriations
Subcommittee on Agriculture, Rural Development, Food and Drug Administration
235 Cannon House Office Building
Washington, DC 20515

The Honorable Sam Farr
Ranking Member
Committee on Appropriations
Subcommittee on Agriculture, Rural Development, and Food and Drug Administration
1126 Longworth Office Building
Washington, DC 20515

Via electronic delivery

Dear Chairmen Rogers, Cole, and Aderholt, and Ranking Members Lowey, DeLauro and Farr:

We thank you and your House 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). The House planned a $300 million increase and your Senate counterparts approved a somewhat larger increase. 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 House to support the full $350 million in Alzheimer’s disease and dementia research funding approved by the Senate Appropriations Committee and to ensure that the FY2016 appropriations agreement is passed without further delay.**

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 House 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. Today, more than five million Americans have dementia at an annual cost to our economy exceeding $200 billion. 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. 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). 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.\textsuperscript{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);\textsuperscript{viii} address health disparities among women,\textsuperscript{ix} African Americans,\textsuperscript{x} Hispanics,\textsuperscript{xi} and persons with intellectual disabilities;\textsuperscript{xii} create a multi-site research consortium to test new treatments for frontotemporal lobar degeneration (FTLD);\textsuperscript{xiii} and pursue cutting-edge trials aimed at preventing or substantially slowing disease progression by administering treatments much earlier in the disease process.\textsuperscript{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.\textsuperscript{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),\textsuperscript{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
Alzheimer's Foundation of America, LEAD Coalition co-convener
Alzheimers North Carolina
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 Federation for Aging Research (AFAR)
American Geriatrics Society
Argentum
Laura D. Baker, PhD (Wake Forest School of Medicine*)
Banner Alzheimer’s Institute
Beating Alzheimer's by Embracing Science
Blanchette Rockefeller Neurosciences Institute
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
Christopher M. Callahan, MD (Indiana University Center for Aging Research*)
Caregiver Action Network
Center for Elder Care and Advanced Illness, Altarum Institute
Center for Alzheimer Research and Treatment, Harvard Medical School
Center for BrainHealth at The University of Texas at Dallas
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
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 College of Medicine*)
Gary Epstein-Lubow, MD (Alpert Medical School of Brown University*)
Fujirebio
Sam Gandy, MD, PhD (Icahn School of Medicine at Mount Sinai*)
Joseph E. Gaugler, Ph.D. (School of Nursing, Center on Aging, University of Minnesota*)
Geoffrey Beene Foundation
Alzheimer's Initiative
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*)
David Holtzman, MD (Washington University School of Medicine, Department of Neurology*)
Home Instead Senior Care
Indiana University Center for Aging Research
Janssen R&D
Johns Hopkins School of Nursing Center for Innovative Care in Aging
Katherine S. Judge PhD (Cleveland State University*)
Keep Memory Alive
Walter A. Kukull, PhD (School of Public Health, University of Washington*)
LatinosAgainstAlzheimer's
LeadingAge
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*)
Mount Sinai Center for Cognitive Health
National Asian Pacific Center on Aging
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
NFL Neurological Center
Thomas O. Obisesan, MD, MPH (Howard University Hospital*)
OWL-The Voice of Women 40+
Pat Summitt Foundation
Planetre
Presence Care Project
Prevent Alzheimer’s Disease 2020
Eric Reiman, MD (Banner Alzheimer's Institute*)
Research!America
ResearchersAgainstAlzheimer's
Stephen Salloway, M.D., M.S. (The Warren Alpert Medical School of Brown University*)
Second Wind Dreams, Inc./Virtual Dementia Tour
Reisa A. Sperling, MD, MMSc (Center for Alzheimer Research and Treatment, Harvard Medical School*)
Rudolph Tanzi, PhD (Department of Neurology, MGH/Harvard Medical School*)
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.
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.