March 12, 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 & Education
2358-B Rayburn House Office Building
Washington, DC 20515

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

Dear Chairmen Rogers and Cole and Ranking Members Lowey and DeLauro:

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. 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 (inflation adjusted 2014 dollars) $1 trillion annually. 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.

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 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. 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; address health disparities among women, African Americans, Hispanics, and persons with intellectual disabilities; and pursue cutting-edge trials aimed at preventing or substantially slowing disease progression by administering treatments much earlier in the disease process.

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. 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), ikrem@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-convener
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 Medicine*)
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
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Gerontological Society of America
Global Coalition on Aging
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David Holtzman, MD (Washington University School of Medicine, Department of Neurology*)
Home Instead Senior Care
Iona Senior Services
Keep Memory Alive
Diana R Kerwin, MD (Texas Alzheimer's and Memory Disorders*)
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, University of Nevada Reno*)
ResearchersAgainstAlzheimer's
Sage Bionetworks
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Reisa A. Sperling, MD, MMSc (Center for Alzheimer Research and Treatment, 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.
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.