March 6, 2018

Dear Senators Collins, Cortez Masto, Capito and Kaine:

Thank you for your leadership on the important public health challenges facing our nation, particularly the urgent issue of Americans living with Alzheimer’s disease and other forms of dementia, including vascular disease, Lewy body dementia, and frontotemporal degeneration. We are pleased to support the bipartisan Building Our Largest Dementia (BOLD) Infrastructure for Alzheimer’s Act (S. 2076/H.R.4256), which would create a public health infrastructure across the country to implement effective interventions focused on dementia public health issues such as increasing early detection and diagnosis, reducing risk and preventing avoidable hospitalizations.

There are few more compelling or complex issues to confront our aging society, now and over the coming decades, than Alzheimer’s disease and other forms of dementia. These neurodegenerative conditions impose enormous costs to our nation’s health, prosperity, and social fabric, costs that are skyrocketing. Based on the National Institute on Aging’s Health and Retirement Study (HRS), we know that the health system costs of caring for people with dementia in the United States are comparable to, and perhaps greater than, those for heart disease and cancer. A recent analysis of HRS data revealed that average per-person health care spending in the last five years of life for people with dementia was more than a $250,000 -- 57 percent greater than costs associated with death from other diseases such as including cancer and heart disease.

Today, more than 5.5 million Americans are living with dementia at an annual cost to our economy exceeding $259 billion. Alzheimer’s disease contributes to the deaths of
approximately 500,000 Americans each year, and it is the only leading cause of death in the United States for which there is no proven means of prevention, disease modification or cure. In a 2011 study, 13.8% of older Asian Americans and Pacific Islander Americans reported an increase in confusion or memory loss, which was the second highest of all ethnic groups. Additionally, researchers have recently estimated that American Indians and Alaska Natives have a 35% lifetime risk of developing dementia. Former Surgeon General and director of the Centers for Disease Control and Prevention (CDC) Dr. David Satcher recently said, "Alzheimer's is the most under-recognized threat to public health in the 21st century." Today, another person develops the disease every 66 seconds; by 2050, someone in the United States will develop the disease every 33 seconds. This explosive growth will cause Alzheimer's costs to increase from an estimated $259 billion in 2017 to $1.1 trillion in 2050 (in 2017 dollars). These mounting costs threaten to bankrupt families, businesses and our health care system.

Public health plays an essential role in protecting the health and well-being of all Americans, including promoting cognitive function and reducing the risk of cognitive decline. Investing in a nationwide public health response to Alzheimer's disease and other forms of dementia would drive population-level change, achieve a higher quality of life for those living with dementia and their caregivers, and reduce associated public and private costs. The BOLD Infrastructure for Alzheimer's Act would provide this crucial investment by establishing centers of excellence across the country and funding state, local and tribal public health departments to increase early detection and diagnosis, reduce risk, prevent avoidable hospitalizations, mitigate health disparities, address the needs of caregivers and support care planning for people living with Alzheimer's disease and other forms of dementia. These important public health actions allow affected individuals to live in their homes longer and delay costly institutionalized care.

The BOLD Infrastructure for Alzheimer's Act would increase the collection, analysis and timely reporting of data critically important to identifying opportunities for public health interventions, helping stakeholders track progress in the public health response, and enabling state and federal policymakers to make informed decisions when developing plans and policies. Comprehensive, disaggregated data collection on Alzheimer's disease and other forms of dementia is essential to better understand the impact of dementia on older Americans, their family members and caregivers – and would strengthen stakeholders’ ability to address dementia-related health disparities among communities of color, American Indian and Alaska Native communities, LGBT communities, and people with intellectual and developmental disabilities. Finally, the bill would strengthen nationwide implementation of the CDC’s Public Health Road Map, which includes strategic action items for state and local public health departments and their partners to promote cognitive functioning, address cognitive impairment and help meet the needs of care partners.

The BOLD Infrastructure for Alzheimer's Act is consistent with the CDC mission, the HHS strategic plan, and the National Alzheimer's Plan goals. The Act would capitalize
on recent updates to the Medicare Physician Fee Schedule that encourage dementia
diagnosis and care planning, the "National Research Summit on Care, Services, and
Supports for Persons with Dementia and Their Caregivers" hosted by NIH last
October, and the CMS "Behavioral Health Payment and Care Delivery Innovation
Summit" held last September. Finally, the Act complements important ongoing work
being done through the Administration on Community Living’s Alzheimer’s Disease
Supportive Services Programs and the Alzheimer’s Disease Initiative.

Thank you for considering our views and for your leadership to overcome Alzheimer’s
disease and other forms of dementia. We look forward to working with you to enact and
implement this essential bipartisan legislation. For any questions or additional
information about this legislation or other policy issues, please contact Ian Kremer,
executive director of Leaders Engaged on Alzheimer’s Disease (the LEAD Coalition),
iki.remer@leadcoalition.org or (571) 383-9916.

Sincerely,

Abe’s Garden Alzheimer’s Center of Excellence
Academy for Radiology & Biomedical Imaging Research
Activists Against Alzheimer’s Network
African American Network Against Alzheimer’s
Paul S. Aisen, MD (Keck School of Medicine of USC, Alzheimer's Therapeutic Research Institute*)
Alliance for Patient Access
Alzheimer's & Dementia Alliance of Wisconsin
Alzheimer's Foundation of America
Alzheimer's Greater Los Angeles
Alzheimer's Mississippi
Alzheimer's New Jersey
Alzheimer's Orange County
Alzheimer's Tennessee
Alzheimer's Texas
AMDA – The Society for Post-Acute and Long-Term Care Medicine
American Academy of Neurology
American Association for Geriatric Psychiatry
American Federation for Aging Research (AFAR)
American Geriatrics Society
American Medical Women’s Association
American Society on Aging
Argentum | Expanding Senior Living
Avanir
Laura D. Baker, PhD (Wake Forest University Health Sciences*)
Banner Alzheimer’s Institute
David M. Bass, PhD (Benjamin Rose Institute on Aging*)
Baylor Scott & White Health
Beating Alzheimer’s by Embracing Science
Benjamin Rose Institute on Aging
Biogen
Biotechnology Innovation Organization (BIO)
B’nai B’rith International
Soo Borson MD (Minnesota Brain Aging Research Collaborative*)
James Brewer, M.D., Ph.D. (UC San Diego and Alzheimer’s Disease Cooperative Study*)
BrightFocus Foundation
Brookdale Senior Living Inc.
Christopher M. Callahan, MD (Indiana University Center for Aging Research*)
Caregiver Action Network
CaringKind, The Heart of Alzheimer’s Caregiving
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 Network
Cleveland Clinic Foundation
Cognition Therapeutics
Suzanne Craft, PhD (Wake Forest School of Medicine*)
Critical Path for Alzheimer’s Disease
Critical Path Institute
Jeffrey Cummings, MD, ScD (Cleveland Clinic Lou Ruvo Center for Brain Health*)
Darrell K. Royal Fund for Alzheimer’s Research
Dementia Alliance International
Department of Neurology, Washington University School of Medicine
Diverse Elders Coalition
Duke (Alzheimer’s) Family Support Program
Eisai Co., Ltd.
ElevatingHOME
Gary Epstein-Lubow, MD (Alpert Medical School of Brown University*)
Faith United Against Alzheimer’s Coalition
Sam Gandy, MD, PhD (Icahn School of Medicine at Mount Sinai*)
Joseph E. Gaugler, PhD (School of Nursing, Center on Aging, University of Minnesota*)
Genentech
Geoffrey Beene Foundation Alzheimer’s Initiative
Daniel R. George, Ph.D, M.Sc (Penn State College of Medicine*)
Georgetown University Medical Center Memory Disorders Program
Gerontological Society of America
Lisa P. Gwyther, MSW, LCSW (Duke University Medical Center*)
Hadassah, The Women’s Zionist Organization of America, Inc.
David M. Holtzman, MD (Washington University School of Medicine, Department of Neurology*)
Home Instead Senior Care
Huffington Center on Aging
Indiana University Center for Aging Research
Janssen R&D
Kathy Jedrziewski, PhD (University of Pennsylvania*)
Johns Hopkins Memory and Alzheimer's Treatment Center
Katherine S. Judge, PhD  
(Cleveland State University*)
Keck School of Medicine of  
USC, Alzheimer's Therapeutic  
Research Institute
Keep Memory Alive
Diana R Kerwin, MD (Texas Alzheimer's  
and Memory Disorders*)
Walter A. Kukull, PhD (School of Public  
Health, University of Washington*)
Latino Alzheimer's and  
Memory Disorders Alliance
LatinosAgainstAlzheimer's
Layton Aging and Alzheimer's Disease  
Center, Oregon Health & Science  
University
LeadingAge
Lewy Body Dementia Association
Linked Senior, Inc
Lundbeck
Kostas Lyketsos, M.D., M.H.S. (Johns  
Hopkins Memory and Alzheimer's  
Treatment Center*)
Medicare Rights Center
Michigan State University Alzheimer's  
Alliance
Minnesota Association of Area Agencies  
on Aging
Minnesota Brain Aging  
Research Collaborative
David G. Morgan, PhD (Michigan State  
University*)
Mount Sinai Center for Cognitive Health
National Alliance for Caregiving
National Asian Pacific Center on Aging
National Association of  
Activity Professionals
National Association of  
Counties (NACo)
National Association of Nutrition and  
Aging Services Programs
National Association of Social Workers  
(NASW)
National Association of States United for  
Aging and Disabilities
National Center for Creative 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 Hospice and Palliative Care  
Organization (NHPCO)
National Indian Council on  
Aging (NICOA)
National Task Group on Intellectual  
Disabilities and Dementia Practices
Neurotechnology Industry Organization
NFL Neurological Center
NYU Alzheimer's Disease Center
NYU Langone Center on  
Cognitive Neurology
NYU Langone Health
Noah Homes
Otsuka America Pharmaceutical Inc  
(OAPI)
Pat Summitt Foundation
Pioneer Network
Piramal Imaging S.A.
Planetree International
Prevent Alzheimer's Disease 2020
Program to Improve Eldercare, Altarum
Peter Reed, PhD (Sanford Center for Aging, University of Nevada Reno*)
Eric Reiman, MD (Banner Alzheimer's Institute*)
ResearchersAgainstAlzheimer's
David B. Reuben, MD (David Geffen School of Medicine at UCLA*)
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 Evangelical Lutheran Good Samaritan Society
The Youth Movement Against Alzheimer's
Geoffrey Tremont, Ph.D., ABPP-CN (Alpert Medical School of Brown University*)
John Q. Trojanowski M.D., Ph.D. (Perelman School of Medicine at the University of Pennsylvania*)
R. Scott Turner, MD, PhD (Georgetown University Memory Disorders Program*)
University of Minnesota School of Nursing, Center on Aging
University of Pennsylvania
Udall Parkinson's Research Center
University of Pennsylvania Center for Neurodegenerative Disease Research
University of Pennsylvania Alzheimer's Disease Core Center
UsAgainstAlzheimer's, LEAD Coalition co-convener
USF Health Byrd Alzheimer's Institute
VeteransAgainstAlzheimer's
Anand Viswanathan, MD, PhD (Massachusetts General Hospital Stroke Research Center/Harvard Medical School*)
Volunteers of America, LEAD Coalition co-convener
Vradenburg Foundation
Peter J. Whitehouse, MD, PhD (Case Western Reserve University*)
Nancy Wilson, MA LCSW (Baylor College of Medicine*)
Wisconsin Alzheimer's Institute, School of Medicine and Public Health, University of Wisconsin-Madison
WomenAgainstAlzheimer's

* Affiliations of individual researchers are for identification purposes only and do not necessarily represent the endorsement of affiliated institutions.
xiv [http://www.leadcoalition.org](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, home and residential care providers, and biotechnology and pharmaceutical companies. The LEAD Coalition works collaboratively to focus the nation’s strategic attention on dementia in all its causes -- including Alzheimer’s disease, vascular disease, Lewy body dementia, and frontotemporal degeneration -- 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.