



March 6, 2018

The Honorable Brett Guthrie  
U.S. House of Representatives  
2434 Rayburn House Office Building  
Washington, D.C. 20515

The Honorable Paul Tonko  
U.S. House of Representatives  
2463 Rayburn House Office Building  
Washington, D.C. 20515

The Honorable Chris Smith  
U.S. House of Representatives  
2373 Rayburn House Office Building  
Washington, D.C. 20515

The Honorable Maxine Waters  
U.S. House of Representatives  
2221 Rayburn House Office Building  
Washington, D.C. 20515

Dear Representatives Guthrie, Tonko, Smith and Waters:

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<sup>i</sup>/H.R.4256<sup>ii</sup>), 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.<sup>iii</sup> 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.<sup>iv</sup>

Today, more than 5.5 million Americans are living with dementia at an annual cost to our economy exceeding \$259 billion.<sup>v</sup> 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.<sup>vi</sup> Hispanics are about 1.5 times more likely to develop Alzheimer's disease than whites, and African Americans are about two times more likely.<sup>vii</sup> 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.<sup>viii</sup> Additionally, researchers have recently estimated that American Indians and Alaska Natives have a 35% lifetime risk of developing dementia.<sup>ix</sup> 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).<sup>x</sup> 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.<sup>xi</sup>

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”<sup>xii</sup> hosted by NIH last October, and the CMS “Behavioral Health Payment and Care Delivery Innovation Summit”<sup>xiii</sup> 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),<sup>xiv</sup> [ikremer@leadcoalition.org](mailto:ikremer@leadcoalition.org) or (571) 383-9916.

Sincerely,

Abe’s Garden Alzheimer’s Center  
of Excellence

Academy for Radiology & Biomedical  
Imaging Research

ActivistsAgainstAlzheimer’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

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Joseph E. Gaugler, PhD (School of Nursing, Center on Aging, University of Minnesota\*)

Genentech

Geoffrey Beene Foundation Alzheimer's Initiative

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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

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LatinosAgainstAlzheimer's  
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University  
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Linked Senior, Inc  
Lundbeck  
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Medicare Rights Center  
Michigan State University Alzheimer's  
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Minnesota Association of Area Agencies  
on Aging  
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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  
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Rudolph Tanzi, PhD (Department  
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The Evangelical Lutheran  
Good Samaritan Society  
The Youth Movement  
Against Alzheimer's  
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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  
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USF Health Byrd Alzheimer's Institute  
VeteransAgainstAlzheimer's  
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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.*

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- i <https://www.congress.gov/bill/115th-congress/senate-bill/2076>
- ii <https://www.congress.gov/bill/115th-congress/house-bill/4256>
- iii <http://www.nejm.org/doi/full/10.1056/NEJMsa1204629>
- iv <http://annals.org/article.aspx?articleid=2466364#>
- v <https://aspe.hhs.gov/system/files/pdf/257526/NatlPlan2017.pdf>
- vi <http://www.neurology.org/content/early/2014/03/05/WNL.0000000000000240>
- vii [http://www.alz.org/documents\\_custom/report\\_alzfactsfigures2010.pdf](http://www.alz.org/documents_custom/report_alzfactsfigures2010.pdf)
- viii [http://napca.org/wp-content/uploads/2017/10/NAPCA954-ActionBrief\\_Policy-5.pdf](http://napca.org/wp-content/uploads/2017/10/NAPCA954-ActionBrief_Policy-5.pdf)
- ix <http://dx.doi.org/10.1016/j.jalz.2015.12.007>
- x [https://www.alz.org/documents\\_custom/2017-facts-and-figures.pdf](https://www.alz.org/documents_custom/2017-facts-and-figures.pdf)
- xi <https://www.cdc.gov/aging/healthybrain/roadmap.htm>
- xii <https://aspe.hhs.gov/national-research-summit-care-services-and-supports-persons-dementia-and-their-caregivers>
- xiii <https://innovation.cms.gov/resources/behavioral-health-paymentcare-summit.html>
- xiv <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.