



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. 2076ⁱ/H.R.4256ⁱⁱ), 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.ⁱⁱⁱ 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.^{iv}

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

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”^{xii} hosted by NIH last October, and the CMS “Behavioral Health Payment and Care Delivery Innovation Summit”^{xiii} 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),^{xiv} 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
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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

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Beating Alzheimer’s by Embracing
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Biogen

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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

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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

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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

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Home Instead Senior Care

Huffington Center on Aging

Indiana University Center for Aging Research

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National Alliance for Caregiving
National Asian Pacific Center on Aging
National Association of
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National Association of
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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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The Evangelical Lutheran
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The Youth Movement
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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
co-convener
USF Health Byrd Alzheimer's Institute
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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
- viii 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
- 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.