



August 18, 2016

The Honorable Chris Smith
United States House of Representatives
2373 House Office Building
Washington, DC 20515

The Honorable Maxine Waters
United States House of Representatives
2221 Rayburn House Office Building
Washington, DC 20515

Dear Representative Smith and Representative Waters:

We write to express our strong support for the Alzheimer's Caregiver Support Act (H.R.3090). This legislation would provide vital support and training to people living with Alzheimer's disease and other forms of dementia and to their caregivers.

Your keen understanding of dementia's enormous personal and societal toll is demonstrated in each of the legislation's key features. The Act addresses dementia in all its forms including Alzheimer's disease, vascular disease, Lewy body dementia, frontotemporal degeneration, and mixed etiologies. Equally important, the Act recognizes that a one-size-fits all approach to care and quality of life must become more tailored and responsive to the heterogeneity of people facing dementia including: women, people in medically under-served areas or ethnically and culturally diverse communities, those with intellectual and developmental disabilities, or with younger-onset disease.

This is a time of great and deserved hope as Congress and the National Institutes of Health have begun to address chronic underfunding of research aiming for scientific breakthroughs to prevent or stop dementia in its tracks by 2025. People living with dementia want breakthroughs and many participate in clinical trials to advance the science. But people living with dementia today cannot rest all their hopes in what science will produce in the coming years. They need what the Act can deliver now. The Act strengthens the ability of community-rooted organizations to improve quality of life for people facing dementia today. The Act strengthens the ability of people living with dementia and their families to access tailored, effective, person-centered services and training where and when it matters most.

We all know the public health, budgetary and macro-economic statistics about dementia. All too many people know first-hand the individual human toll. You have been vocal, powerful and effective voices for millions of people across this country whose personal stories demand attention and demand change. The Act gives voice to the fundamental truth that people living with dementia need not only hope for the future but also improved quality of life today.

Thank you for considering our views and for your commitment to overcoming Alzheimer's disease and other forms of dementia. Please contact Ian Kremer, executive director of Leaders Engaged on Alzheimer's Disease (the LEAD Coalition),¹ ikremer@leadcoalition.org or (571) 383-9916, with questions or for additional information.

Sincerely,

Abe's Garden

Academy of Radiology Research

ACT on Alzheimer's

ActivistsAgainstAlzheimer's

African American Network
Against Alzheimer's

Paul S. Aisen, MD (Keck School of
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Allergan

Alliance for Aging Research

Alzheimer's & Dementia Alliance
of Wisconsin

Alzheimer's Foundation of America

Alzheimer's Greater Los Angeles

Alzheimer's Mississippi

Alzheimer's Orange County

Alzheimer's San Diego

Alzheimer's Tennessee

AMDA – The Society for Post-Acute and
Long-Term Care Medicine

American Association for Geriatric
Psychiatry

ARGENTUM | Expanding Senior Living

Laura D. Baker, PhD (Wake Forest School
of Medicine*)

Banner Alzheimer's Institute

David M. Bass, PhD (Benjamin Rose
Institute on Aging*)

Beating Alzheimer's by Embracing
Science

Benjamin Rose Institute on Aging

Biogen

B'nai B'rith International

Soo Borson MD (University of Washington
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San Diego and Alzheimer's
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BrightFocus Alzheimer's
Disease Research

Christopher M. Callahan, MD
(Indiana University Center for
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Caregiver Action Network

CaringKind

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

Coalition for Imaging and Bioengineering
Research

CorTechs Labs

Critical Path Institute/ Coalition Against
Major Diseases

Cure Alzheimer's Fund

Darrell K. Royal Fund for
Alzheimer's Research

Dementia Alliance International

Dementia Friendly America

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Geoffrey Beene Foundation Alzheimer's Initiative

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Johns Hopkins Memory and Alzheimer's Treatment Center

Johns Hopkins School of Nursing Center for Innovative Care in Aging

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Keck School of Medicine of USC, Alzheimer's Therapeutic Research Institute

Walter A. Kukull, PhD (School of Public Health, University of Washington*)

LatinosAgainstAlzheimer's

Latino Alzheimer's and Memory Disorders Alliance

LeadingAge

Lewy Body Dementia Association

Linked Senior, Inc.

LuMind Research Down Syndrome Foundation

Lundbeck

Lutheran Services of America

Kostas Lyketsos, M.D., M.H.S. (Johns Hopkins Memory and Alzheimer's Treatment Center*)

David G. Morgan, PhD (USF Health Byrd Alzheimer's Institute*)

Mount Sinai Center for Cognitive Health

National Alliance for Caregiving

National Asian Pacific Center on Aging

National Association of Activity Professionals

National Association of Nutrition and Aging Services Programs

National Association of States United for Aging and Disabilities

National Caucus and Center on Black Aged, Inc. (NCBA)

National Committee to Preserve Social Security and Medicare

National Consumer Voice for Quality Long-Term Care

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

NFL Neurological Center

NYU Alzheimer's Disease Center

NYU Langone Center on Cognitive Neurology

NYU Langone Medical Center

Noah Homes

OWL-The Voice of Women 40+
Pat Summitt Foundation
Pioneer Network
Piramal Imaging S.A.
Planetree
Presence Care Project
Prevent Alzheimer's Disease 2020
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The Association for Frontotemporal
Degeneration
The Eden Alternative
The Evangelical Lutheran Good Samaritan
Society
The Youth Movement Against Alzheimer's
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WomenAgainstAlzheimer's

** Affiliations of individual researchers are for identification purposes only and do not necessarily represent the endorsement of the affiliated institution.*

ⁱ <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, and 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.