



August 18, 2016

The Honorable Peter Roskam
United States House of Representative
2246 Rayburn House Office Building
Washington, DC 20515

The Honorable Linda Sánchez
United States House of Representatives
2329 Rayburn House Office Building
Washington, DC 20515

Dear Representative Roskam and Representative Sánchez:

We write to express our strong support for the Alzheimer's Beneficiary and Caregiver Support Act (H.R.5681). The Act would help improve quality of life for people living with Alzheimer's disease and other forms of dementia, support family care partners, and reduce costs to federal and state health programs.

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. In that spirit, the bill calls on the Centers for Medicare and Medicaid Services (CMS) to launch pilot projects using a variety of caregiver support services to help people living with dementia stay in their preferred home setting for longer periods of time, resulting in lower Medicare and Medicaid program costs.

Your bipartisan legislation recognizes that targeted counseling and supportive services delivered to family care partners can delay the use of institutional care. Under the Act, CMS would test such supportive models for family caregivers of Medicare beneficiaries diagnosed with dementia. The models would include individual and family counseling sessions, follow-up assessments, support groups and ad hoc counseling or consultations, depending on the health of the applicable Medicare beneficiary. One such model, evaluated over more than two decades in New York and replicated in other settings, demonstrated that targeted supports enable people with dementia to remain at home longer – averaging a year and-a-half longer -- than people whose care partners did not receive such supports.

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 family care partners 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), ikremer@leadcoalition.org or (571) 383-9916, with questions or for additional information.

Sincerely,

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Academy of Radiology Research
ACT on Alzheimer's
ActivistsAgainstAlzheimer's
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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
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 National Association of Activity
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 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
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 Rudolph Tanzi, PhD (Department of Neurology, MGH/Harvard Medical School*)
 The Association for Frontotemporal Degeneration
 The Eden Alternative
 The Evangelical Lutheran Good Samaritan Society
 The Youth Movement Against Alzheimer's
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 UsAgainstAlzheimer's, LEAD Coalition co-convenor
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 Volunteers of America, LEAD Coalition co-convenor
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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.