



September 23, 2013

The Honorable Fred Upton  
Chairman  
Committee on Energy & Commerce  
United States Congress  
2125 Rayburn House Office Building  
Washington, DC 20515

The Honorable Henry Waxman  
Ranking Member  
Committee on Energy & Commerce  
United States Congress  
2322A Rayburn House Office Building  
Washington, DC 20515

The Honorable Joe Pitts  
Chairman  
Committee on Energy & Commerce  
Subcommittee on Health  
2125 Rayburn House Office Building  
Washington, DC 20515

The Honorable Frank Pallone  
Ranking Member  
Committee on Energy & Commerce  
Subcommittee on Health  
2322A Rayburn House Office Building  
Washington, DC 20515

**VIA ELECTRONIC DELIVERY**

Dear Chairmen Upton and Pitts and Ranking Members Waxman and Pallone:

We applaud Congress and the Administration for recognizing and responding decisively to the challenges of Alzheimer's disease and related disorders by enacting the National Alzheimer's Project Act (Public Law 111-375), which has produced the National Plan to Address Alzheimer's Disease<sup>1</sup>. To help advance the goals set out in the National Plan, including preventing and treating Alzheimer's disease by 2025, we strongly encourage the Committee on Energy & Commerce to convene a hearing this fall on Alzheimer's disease and related disorders.

In addition to preventing and effectively treating Alzheimer's disease by 2025, the National Plan includes the goals of optimizing quality and efficiency of care, expanding supports for patients and families, and increasing public awareness of the disease. Progress is occurring on the National Plan's goals and the first update was released earlier this year. Given the pace and urgency of the dementia crisis confronting our nation, this fall would be an opportune time for the committee to convene a comprehensive hearing on National Plan implementation.

The current and projected impact of Alzheimer's disease on our nation's health and finances – both public and personal – is immense. Today, over five million Americans have Alzheimer's disease -- and millions more have vascular, Lewy body or frontotemporal dementia -- at a total cost exceeding \$200 billion annually. A recent study<sup>ii</sup> by the RAND Corporation, pegged the total costs of purchased dementia care at \$109 billion in 2010, more than costs associated with heart disease and cancer. As our Nation ages, it is expected that 13 million or more Americans will have Alzheimer's disease and total costs of care are projected to exceed (inflation adjusted) \$1 trillion annually by 2050. The federal government, through Medicare and Medicaid payments, shoulders an estimated 70 percent of all such costs.

A national crisis like Alzheimer's disease warrants the continued attention of leaders in Congress and your committee has the jurisdiction and is uniquely well suited to conduct the first comprehensive hearing examining Alzheimer's disease and related disorders including implementation of the National Plan. A comprehensive Alzheimer's disease hearing could include government and non-government witnesses in multiple sectors including biomedical research, biopharmaceutical development, clinical care, patient and caregiver support, health insurance and reimbursement, and public health. It could examine public and private sector actions to achieve the National Plan's goals and flag emergent barriers and gaps. It would provide committee members the opportunity to raise important questions about whether the public and private sectors are cutting through the red tape, incentivizing innovation, fostering collaboration, and seizing every opportunity to accelerate the end of Alzheimer's disease and related disorders.

[Leaders Engaged on Alzheimer's Disease](#) (LEAD)<sup>iii</sup> and its member organizations would be more than happy to assist in the planning this or any other hearing on Alzheimer's disease and related disorders, including identifying or serving as witnesses.

Thank you for considering our recommendation and for your commitment to overcoming Alzheimer's disease and related disorders. Please contact Ian Kremer, the LEAD Coalition's executive director, at [ikremer@leadcoalition.org](mailto:ikremer@leadcoalition.org) or (571) 383- 9916, with questions or for additional information.

Sincerely,

Abe's Garden

Academy of Radiology Research

African American Network Against  
Alzheimer's

Alliance for Aging Research

Alzheimer's & Dementia Alliance of  
Wisconsin

Alzheimer's Foundation of America

Alzheimer's Tennessee

AMDA – Dedicated to Long Term Care  
Medicine<sup>TM</sup>

American Academy of Neurology	Gerontological Society of America
American Association for Geriatric Psychiatry	Global Coalition on Aging
American Association for Long Term Care Nursing	Inspire
American Geriatrics Society	Janssen Alzheimer Immunotherapy
Assisted Living Federation of America	Janssen Research & Development, LLC
Laura D. Baker, PhD (Wake Forest School of Medicine*)	Keep Memory Alive
Banner Alzheimer's Institute	Latino Alzheimer's and Memory Disorders Alliance
Beating Alzheimer's by Embracing Science	LeadingAge
BrightFocus Alzheimer's Disease Research	Lewy Body Dementia Association
Caregiver Action Network	Linked Senior, Inc.
Center for Alzheimer Research and Treatment, Harvard Medical School	Kostas Lyketsos, M.D., M.H.S. (Johns Hopkins Memory and Alzheimer's Treatment Center*)
Cleveland Clinic Foundation	Dave Morgan, PhD (USF Health Byrd Alzheimer's Institute*)
Coalition for Imaging and Bioengineering Research	National Alliance for Caregiving
Cognition Therapeutics	National Association of States United for Aging and Disabilities
Cortica Neurosciences, Inc.	National Caucus and Center on Black Aged, Inc.
Critical Path Institute	National Consumer Voice for Quality Long-Term Care
Jeffrey Cummings, MD, ScD (Cleveland Clinic Lou Ruvo Center for Brain Health*)	National Down Syndrome Society
Cure Alzheimer's Fund	National Task Group on Intellectual Disabilities and Dementia Practices
Darrell K. Royal Fund for Alzheimer's Research	Neurotechnology Industry Organization
Rachelle S. Doody, MD, PhD (Baylor College of Medicine*)	New York Academy of Sciences
Friends of the National Institute on Aging	NYU Langone Comprehensive Center on Brain Aging/NYU Langone Silberstein Alzheimer's Institute
Geoffrey Beene Foundation - Alzheimer's Initiative	NYU Alzheimer's Disease Center
Georgetown University Medical Center Memory Disorders Program	OWL-The Voice of Midlife and Older Women
	Pat Summitt Foundation

Piramal Imaging	R. Scott Turner, MD, PhD
RemeGenix, Inc.	(Georgetown University Memory Disorders Program*)
Research!America	USAgainstAlzheimer's
ResearchersAgainstAlzheimer's	USF Health Byrd Alzheimer's Institute
Stephen Salloway, M.D., M.S. (The Warren Alpert Medical School of Brown University*)	Volunteers of America
Reisa A. Sperling, MD, MMSc (Center for Alzheimer Research and Treatment, Harvard Medical School*)	Vradenburg Foundation
Taos Health Systems	Washington University School of Medicine, Department of Neurology (St. Louis, Missouri)
The Association for Frontotemporal Degeneration	Michael W. Weiner, MD (University of California San Francisco*)
	WomenAgainstAlzheimer's

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

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<sup>i</sup> <http://aspe.hhs.gov/daltcp/napa/NatlPlan2013.shtml>

<sup>ii</sup> <http://www.nejm.org/doi/pdf/10.1056/NEJMsa1204629>

<sup>iii</sup> LEAD (<http://www.leadcoalition.org>) is a diverse and growing coalition of 61 member organizations including patient advocacy and voluntary health non-profits, philanthropies and foundations, trade and professional associations, academic research and clinical institutions, and biotechnology and pharmaceutical companies. The LEAD Coalition works collaboratively to focus the nation's strategic attention on Alzheimer's disease and related disorders and to accelerate transformational progress in care and support, detection and diagnosis, and research leading to prevention, effective treatment and eventual cure. One or more participants may have a financial interest in the subjects addressed.