



July 16, 2014

Cecilia Muñoz, Director
Domestic Policy Council
Assistant to the President
The White House
1600 Pennsylvania Avenue, NW
Washington, DC 20500

VIA ELECTRONIC DELIVERY

Dear Director Muñoz:

Leaders Engaged on Alzheimer's Disease (LEAD Coalition)ⁱ deeply appreciates and applauds President Obama and the Administration for historic leadership in addressing Alzheimer's disease and related dementias from signing into law the National Alzheimer's Project Act and issuing the National Plan to Address Alzheimer's Disease, to winning record increases in research and support funding and bringing American leadership to the global dementia effort. These and so many other efforts by this Administration to take dementia out of the shadows and onto center stage as a national priority give us full confidence as **we offer our robust support to the convening of a White House Conference on Aging (WHCOA) in 2015.**

We encourage the Administration and all those involved in planning and implementing the 2015 WHCOA to integrate Alzheimer's disease and related dementias as a crosscutting theme in every convening, each analysis, and all recommendations because no one -- and no issue -- is beyond the devastating reach of dementia.

The 2015 WHCOA will focus national aging policy for the next ten years to 2025, coincidentally and appropriately the target year established by the National Plan by which to achieve a means of preventing and effectively treating dementia.ⁱⁱ There are few more compelling or complex issues to confront our aging society over the next decade than Alzheimer's disease and related dementias (including vascular, Lewy body or frontotemporal dementia) which currently impose enormous costs to our nation's health and prosperity, costs that are skyrocketing.ⁱⁱⁱ Today, more than five million Americans^{iv} have dementia at an annual cost to our economy exceeding \$200 billion.^v Alzheimer's disease contributes to the deaths of approximately 500,000 Americans each year, making it the third leading cause of death in the United States.^{vi} If the current trajectory of the disease persists, more than 13 million Americans will have dementia in 2050 and total costs of care are projected to exceed (inflation adjusted 2014 dollars) \$1

trillion annually.^{vii} The federal government, through Medicare and Medicaid payments, shoulders an estimated 70 percent of all such direct care costs.

For people living with dementia, their families and caregivers, and those rightly concerned that dementia may be on their horizon, it affects: housing; employment; poverty; crime; safety; re-hospitalization (directly and in its complication of co-morbid conditions); immigration; grandparenting; transportation; nutrition; isolation; abuse, neglect and exploitation; and myriad other issues. Dementia touches the lives of virtually every older American while fundamentally shaping both the range of policy options and the efficacy of those options in nearly every facet of life. We cannot imagine any aspect of preparing for, conducting or acting upon the work of a meaningful 2015 WHCOA that could exclude consideration of dementia.

We also recommend that the 2015 WHCOA include a dementia-specific track following the broad outlines of the National Plan to Address Alzheimer's Disease. The track should examine not only the Plan's progress but also gaps and ways to further realize the vision that the Plan should be genuinely "national," not just "federal." The Plan rightly has placed tremendous emphasis on drug discovery to effectively prevent or treat Alzheimer's disease and related disorders by 2025 along with the Plan's other top-line goals for strengthening clinical care and long-term services and support. But there is room and merit in increasing attention and diving deeper on actions aimed at: reducing stigma^{viii} and increasing community integration of people with dementia and their family caregivers^{ix} while providing resources to help family caregivers deliver home-based care for as long as possible;^x improving methods of earlier and more accurate detection and diagnosis while advancing research in non-pharmacological interventions;^{xi} investigating the genetic risk factors^{xii} while addressing the disproportionate impact on women,^{xiii} African Americans,^{xiv} Hispanics,^{xv} and persons with intellectual disabilities;^{xvi} identifying and adapting best practices in science, care and support from other countries while fostering collaborations between a diverse range of private sector stakeholders and their local, state and federal government counterparts.^{xvii}

Because dementia is woven into the fabric of every aspect of aging in America and the LEAD Coalition is blessed with diverse member and allied organizations, we are ready, willing and enthusiastic to offer our participation and support at every opportunity surrounding the 2015 WHCOA. We are prepared to provide or refer experts, mobilize constituents, offer promotional support, contribute analysis and recommendations, nominate delegates – including people living with dementia and family caregivers -- to the 2015 WHCOA, and advocate for and implement changes to improve the outlook for older Americans.

Thank you for considering our views 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 or (571) 383-9916, with questions or for additional information.

Sincerely,

Abe's Garden	Blanchette Rockefeller Neurosciences Institute
Academy of Radiology Research	B'nai B'rith International
ActivistsAgainstAlzheimer's	Alice Bonner, PhD, RN (Northeastern University Bouve' College of Health Sciences*)
Advancing Excellence in America's Nursing Homes Campaign	James Brewer, M.D., Ph.D. (UC San Diego and Alzheimer's Disease Cooperative Study*)
African American Network Against Alzheimer's	BrightFocus Foundation
Aging and Memory Disorder Programs, Howard University	Brookdale Senior Living Solutions
Alzheimers North Carolina	Byrd Alzheimer's Institute, University of South Florida
Alzheimer's & Dementia Alliance of Wisconsin	Caregiver Action Network
Alzheimer's Drug Discovery Foundation	Center for Alzheimer Research and Treatment, Harvard Medical School
Alzheimer's Foundation of America, LEAD Coalition co-convener	Center for BrainHealth at The University of Texas at Dallas
Alzheimer's Tennessee	Sandra Bond Chapman, PhD (Center for BrainHealth at The University of Texas at Dallas*)
AMDA – The Society for Post-Acute and Long-Term Care Medicine	ClergyAgainstAlzheimer's
American Academy of Neurology	Cleveland Clinic Foundation
American Association for Geriatric Psychiatry	Coalition for Imaging and Bioengineering Research
American Association for Long Term Care Nursing	Cognition Therapeutics
American Brain Coalition	CorTechs Labs
American Geriatrics Society	Cortica Neurosciences, Inc.
American Health Care Association/National Center for Assisted Living	Critical Path Institute
Assisted Living Federation of America	Jeffrey Cummings, MD, ScD (Cleveland Clinic Lou Ruvo Center for Brain Health*)
Laura D. Baker, PhD (Wake Forest School of Medicine*)	Cure Alzheimer's Fund
Banner Alzheimer's Institute	

Darrell K. Royal Fund for Alzheimer's Research

Department of Neurology, Washington University in St. Louis

Rachelle S. Doody, MD, PhD (Baylor College of Medicine*)

Eli Lilly and Company

Geoffrey Beene Foundation Alzheimer's Initiative

Georgetown University Medical Center Memory Disorders Program

Gerontological Society of America

Global Coalition on Aging

Hearthstone Alzheimer Care

David Holtzman, MD (Washington University School of Medicine, Department of Neurology*)

Home Instead Senior Care

Inspire

Iona Senior Services

Janssen Research & Development, LLC

Keep Memory Alive

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

LatinosAgainstAlzheimer's

Lewy Body Dementia Association

Linked Senior, Inc.

LuMind Foundation (formerly Down Syndrome Research and Treatment Foundation)

Memory Training Centers of America

Merck

David G. Morgan, PhD (Byrd Alzheimer's Institute, University of South Florida*)

National Alliance for Caregiving

National Association of Chronic Disease Directors

National Association of Nutrition and Aging Services Programs

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

National Consumer Voice for Quality Long-Term Care

National Down Syndrome Society

National Hispanic Council On Aging (NHCOA)

National Task Group on Intellectual Disabilities and Dementia Practices

Neurotechnology Industry Organization

New Jersey Alliance for Culture Change

New York Academy of Sciences

NYU Alzheimer's Disease Center

NYU Langone Center on Cognitive Neurology

Thomas O. Obisesan, MD, MPH (Howard University Hospital*)

OWL-The Voice of Women 40+

Pat Summitt Foundation

Pfizer, Inc.

Pioneer Network

Piramal Imaging S.A.

Project Lifesaver International	Taos Health Systems
Peter Reed, PhD (Sanford Center for Aging, University of Nevada Reno*)	The Association for Frontotemporal Degeneration
RemeGenix, Inc.	The Eden Alternative
ResearchersAgainstAlzheimer's	THE GREEN HOUSE® Project
Sage Bionetworks	The I'm Still Here Foundation
Stephen Salloway, M.D., M.S. (The Warren Alpert Medical School of Brown University*)	R. Scott Turner, MD, PhD (Georgetown University Memory Disorders Program*)
Reisa A. Sperling, MD, MMSc (Center for Alzheimer Research and Treatment, Harvard Medical School*)	USAgainstAlzheimer's, LEAD Coalition co-convenor
Rudolph Tanzi, PhD (Department of Neurology, MGH/Harvard Medical School*)	Volunteers of America
	Wisconsin Alzheimer's Institute
	Women Against Alzheimer's

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

ⁱ Leaders Engaged on Alzheimer's Disease (LEAD Coalition), <http://www.leadcoalition.org>, is a diverse and growing national coalition of 67 member organizations including patient advocacy and voluntary health non-profits, philanthropies and foundations, trade and professional associations, academic research and clinical institutions, and homecare, biotechnology and pharmaceutical companies. The LEAD Coalition works collaboratively to focus the nation's strategic attention on Alzheimer's disease and related dementias -- including vascular, Lewy body or frontotemporal dementia -- 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.

ⁱⁱ <http://aspe.hhs.gov/daltcp/napa/NatIPlan.pdf>

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

^{iv} <http://aspe.hhs.gov/daltcp/napa/NatIPlan2014.pdf>

^v <http://www.nejm.org/doi/pdf/10.1056/NEJMsa1204629>

^{vi} <http://www.neurology.org/content/early/2014/03/05/WNL.0000000000000240>

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- vii <http://www.alz.org/trajectory>
- viii <http://www.alz.co.uk/research/world-report-2012>
- ix <http://www.actonalz.org/node/97>
- x <http://www.alzfdn.org/documents/Quantifying-Care-Centered-Provisions-of-the-National-Plan-to-Address-Alzheimers-Disease.pdf>
- xi <http://www.nia.nih.gov/alzheimers/publication/2012-2013-alzheimers-disease-progress-report/advancing-discovery-alzheimers#priorities>
- xii <http://www.nia.nih.gov/alzheimers/publication/2012-2013-alzheimers-disease-progress-report/genetics-alzheimers-disease>
- xiii http://www.alz.org/downloads/facts_figures_2014.pdf
- xiv http://www.usagainstalzheimers.org/sites/default/files/USA2_AAN_CostsReport.pdf
- xv <http://www.nhcoa.org/wp-content/uploads/2013/05/NHCOA-Alzheimers-Executive-Summary.pdf>
- xvi http://aadmd.org/sites/default/files/NTG_Thinker_Report.pdf
- xvii http://www.rand.org/pubs/research_reports/RR597.html