



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,

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| 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 | |

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| Darrell K. Royal Fund for Alzheimer's Research | Merck |
| Department of Neurology, Washington University in St. Louis | David G. Morgan, PhD (Byrd Alzheimer's Institute, University of South Florida*) |
| Rachelle S. Doody, MD, PhD (Baylor College of Medicine*) | National Alliance for Caregiving |
| Eli Lilly and Company | National Association of Chronic Disease Directors |
| Geoffrey Beene Foundation Alzheimer's Initiative | National Association of Nutrition and Aging Services Programs |
| Georgetown University Medical Center Memory Disorders Program | National Caucus and Center on Black Aged, Inc. (NCBA) |
| Gerontological Society of America | National Consumer Voice for Quality Long-Term Care |
| Global Coalition on Aging | National Down Syndrome Society |
| Hearthstone Alzheimer Care | National Hispanic Council On Aging (NHCOA) |
| David Holtzman, MD (Washington University School of Medicine, Department of Neurology*) | National Task Group on Intellectual Disabilities and Dementia Practices |
| Home Instead Senior Care | Neurotechnology Industry Organization |
| Inspire | New Jersey Alliance for Culture Change |
| Iona Senior Services | New York Academy of Sciences |
| Janssen Research & Development, LLC | NYU Alzheimer's Disease Center |
| Keep Memory Alive | NYU Langone Center on Cognitive Neurology |
| Walter A. Kukull, PhD (School of Public Health, University of Washington*) | Thomas O. Obisesan, MD, MPH (Howard University Hospital*) |
| LatinosAgainstAlzheimer's | OWL-The Voice of Women 40+ |
| Lewy Body Dementia Association | Pat Summitt Foundation |
| Linked Senior, Inc. | Pfizer, Inc. |
| LuMind Foundation (formerly Down Syndrome Research and Treatment Foundation) | Pioneer Network |
| Memory Training Centers of America | Piramal Imaging S.A. |

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| 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-convener |
| 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.000000000000240>

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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