



February 11, 2015

The Honorable Susan Collins
Chairman Special Committee on Aging
United States Senate
413 Dirksen Senate Office Building
Washington, DC 20510

Dear Chairman Collins:

As executive director of Leaders Engaged on Alzheimer's Disease (the LEAD Coalition)ⁱ, I write to thank you for your inspirational leadership in reintroducing the Senate resolution to strengthen care and support, encourage greater international collaboration, incentivize private sector research, double federal investments in Alzheimer's disease and related dementias research in FY 2016, and bring annual federal investments to at least \$2 billion by 2020. **Your resolution is an important next step toward each of these vital goals and the LEAD Coalition will continue to work arm-in-arm with you and your colleagues to realize the resolution's promise.**

There are few more compelling or complex issues to confront our aging society now and over the coming decades than Alzheimer's disease and related dementias (including vascular, Lewy body or frontotemporal dementia). Its place as a national priority was made clear by the effort you led resulting in unanimous congressional passage of the National Alzheimer's Project Act. That law directed creation of the National Plan to Address Alzheimer's Disease and, as you know, the National Plan's goal number one is to prevent and effectively treat Alzheimer's disease and related dementias by 2025.ⁱⁱ

In fact, as your resolution highlights, Alzheimer's disease and related dementias are an urgent national priority that 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, between 13 million and 16 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.

Globally, the stakes of American scientific leadership are higher still. Today, 44 million people have dementia^{viii} with annual costs exceeding \$600 billion or about one percent of the world's GDP.^{ix} If the current trajectory of the disease persists, upwards of 135 million persons worldwide will have dementia in 2050.^x American scientific leadership is nowhere more urgent than in Alzheimer's disease and related dementias.

Congress, the President and NIH Director Dr. Francis Collins have overcome enormous obstacles to increase funding and prioritization of Alzheimer's disease and related dementias research over the past several years. The National Institute on Aging (NIA) and other NIH institutes -- such as the National Institute of Neurological Disorders and Stroke, the National Institute of Biomedical Imaging and Bioengineering, the National Institute of Mental Health and the National Institute of Child Health and Human Development -- are supporting a number of promising research projects to: understand the genetic risk factors;^{xi} address the disproportionate impact on women,^{xii} African Americans,^{xiii} Hispanics,^{xiv} and persons with intellectual disabilities;^{xv} and pursue cutting-edge but costly and time consuming trials aimed at preventing or substantially slowing disease progression by administering treatments much earlier in the disease process.^{xvi} These resources of time, talent and treasure are precious and indefensibly scarce. We owe it to the taxpayers, to the research community and -- most of all -- to people living with, or at risk of, Alzheimer's disease and related dementias to provide adequate and necessary resources proportionate to the disease burden, unmet medical need, and our nation's ethical and moral compass.

The broad, diverse, and unified Alzheimer's disease and related dementias community -- working together as the LEAD Coalition -- deeply admires and appreciates your remarkable leadership on this and so many other issues of vital importance to our nation's cognitive health, economic well-being, and global scientific leadership. We look forward to working with you for passage of the resolution and subsequent congressional action on each of its goals.

Sincerely,



Ian Kremer, Esq.
Executive Director
LEAD Coalition

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 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/NatlPlan.pdf>

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

iv <http://aspe.hhs.gov/daltcp/napa/NatlPlan2014.pdf>

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

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

vii <http://www.alz.org/trajectory>

viii <http://www.alz.co.uk/research/GlobalImpactDementia2013.pdf>

ix http://www.nia.nih.gov/sites/default/files/global_health_and_aging.pdf

x <http://www.alz.co.uk/research/GlobalImpactDementia2013.pdf>

xi <http://www.nia.nih.gov/alzheimers/publication/2012-2013-alzheimers-disease-progress-report/genetics-alzheimers-disease>

xii http://www.alz.org/downloads/facts_figures_2014.pdf

xiii http://www.usagainstalzheimers.org/sites/default/files/USA2_AAN_CostsReport.pdf

xiv <http://www.nhcoa.org/wp-content/uploads/2013/05/NHCOA-Alzheimers-Executive-Summary.pdf> and http://www.usagainstalzheimers.org/sites/all/themes/alzheimers_networks/files/LatinosAgainstAlzheimers_Issue_Brief.pdf

xv http://aadmd.org/sites/default/files/NTG_Thinker_Report.pdf

xvi <http://www.nia.nih.gov/alzheimers/publication/2012-2013-alzheimers-disease-progress-report/advancing-discovery-alzheimers#priorities>