



February 11, 2013

The Honorable Harry Reid  
Majority Leader  
United States Senate  
S-221 U.S. Capitol  
Washington, DC 20510

The Honorable Mitch McConnell  
Minority Leader  
United States Senate  
S-230 U.S. Capitol  
Washington, DC 20510

The Honorable John Boehner  
Speaker of the House  
United States House of Representatives  
H-232 U.S. Capitol  
Washington, DC 20515

The Honorable Nancy Pelosi  
Minority Leader  
United States House of Representatives  
H-204 U.S. Capitol  
Washington, DC 20515

***VIA ELECTRONIC DELIVERY***

Dear Majority Leader Reid, Speaker Boehner, Minority Leader McConnell and Minority Leader Pelosi:

Less than one year ago, the U.S. Department of Health and Human Services issued the landmark National Plan to Address Alzheimer's Disease that enumerates as its goals to: 1) Prevent and Effectively Treat Alzheimer's Disease by 2025; 2) Optimize Care Quality and Efficiency; 3) Expand Supports for People with Alzheimer's Disease and Their Families; 4) Enhance Public Awareness and Engagement; and 5) Track Progress and Drive Improvement. Enacted as part of the National Alzheimer's Project Act, which was passed unanimously by Congress, the plan is the nation's recognition of the urgency posed by the current and looming Alzheimer's disease and related dementias crisis, one that threatens to destroy our nation's health and finances if inadequately addressed. Yet, automatic cuts through sequestration will thwart any progress made by the national Alzheimer's plan by cutting numerous vital programs, including: basic and translational research funding at the National Institutes of Health (NIH); funding for the regulatory approval and user fees processes at the Food & Drug Administration (FDA); and, federal programs that support individuals with dementia, family and paid caregivers at the Administration on Aging (AoA), the Health Resources and Services Administration (HRSA), and other agencies.

Achieving the Alzheimer's disease national plan goals will be impossible if the deep and unsustainable cuts to valuable Alzheimer's disease research, public health, and patient and caregiver support programs take effect next month. As leaders of the united Alzheimer's research, clinical care, and patient and caregiver support community, we are writing to urge that you recognize this reality and take action to protect vital programs from the sequester.

At this time last year, the Alzheimer's community was pleased that the Administration allocated an additional \$50 million to Alzheimer's biomedical research programs at the NIH. This funding supports cutting edge research projects such as seeking to prevent onset of Alzheimer's in those genetically likely to develop Alzheimer's and exploring insulin as a treatment for the disease. Despite its immense impact on the nation's health and finances – more than 5 million Americans with this devastating disease at a cost of \$200 billion this year alone on a path to exceeding 15 million sufferers at a cost of more than \$1 trillion annually over the coming decades – the government's commitment to Alzheimer's research has lagged considerably behind support for research into other high-prevalence and high-cost diseases. The allocation of an additional \$50 million to Alzheimer's research represents a monetarily modest yet symbolically and scientifically significant step to reverse long-standing underinvestment.

The benefits of the \$50 million research funding infusion provided in Fiscal Year 2012 will be sharply undermined by the sequester, with NIH estimated to incur a total loss of about \$2.5 billion. For Alzheimer's, this would mean that solicitations issued last fall would go unfunded for research proposals in genetic analysis, identification and validation of potential therapeutic targets, early stage clinical trials and additional support for groundbreaking prevention trials. While substantial and critical, the federal commitment to Alzheimer's research is a fraction of the total amount of money provided by industry, academia, and venture philanthropists, among others. A robust federal commitment to Alzheimer's research helps attract, sustain, and leverage other sources of funding to accelerate the most promising research initiatives, and that support is at significant risk if the sequester is implemented.

In addition to Alzheimer's research, the sequester threatens to decimate workforce training, clinical care, patient and caregiver support programs including those helping family caregivers sustain immense challenges associated with this labor of love. For example, HRSA's Title VII and VIII Geriatrics Workforce Training Programs are necessary to support training the healthcare workforce and to foster groundbreaking medical research preparing our nation to meet the unique health care needs of the rapidly growing senior population. Similarly, the Centers for Medicare & Medicaid Services (CMS) provides critical nursing home training programs and the National Partnership to Improve Dementia Care in Nursing Homes to deliver health care that is person-centered, comprehensive and interdisciplinary; this will help reduce unnecessary use of antipsychotic medications. While we recognize the fiscal challenges facing our nation, sustained and enhanced federal investments in these initiatives are essential to delivering higher quality, better coordinated, and more cost effective care to our nation's seniors.

Sequestration's non-defense discretionary cuts in FY 2013 would devastate federal programs that maintain older adults, including those with Alzheimer's disease or a related dementia. These programs allow people with Alzheimer's disease to remain at home longer and provide family caregivers needed respite. Any "savings" from sequestration would pale in comparison to the added costs from unnecessary hospitalizations and premature nursing home placements, and greater physical, emotional, and financial strains -- already exceeding \$45 billion annually in out-of-pocket costs -- on America's over 15 million Alzheimer's disease family caregivers.

The Older Americans' Act (OAA) provides flexible funding to state and local agencies to deliver a wide range of supportive services to seniors, many of whom have Alzheimer's disease, and their caregivers. Sequestration cuts to OAA would result in the loss of:

- 1.9 million transportation rides for seniors to medical appointments, grocery shopping and other primary needs;
- 290,000 older adults of case management services that coordinate care essential to remaining at home;
- 1.2 million older adults of homemaker services that help with basic housekeeping needs such as cooking or laundry;
- 1.5 million people of personal care services such as in-home assistance with bathing, toileting and dressing;
- 750,000 individuals in adult day programs of access to the health care, socialization and nutrition they—and family caregivers—rely upon at these programs; and
- 75,000 seniors of OAA legal services, while elder abuse and fraud are on the rise.

The OAA's National Family Caregiver Support Program (NFCSP) plays a critical role in supporting family caregivers who deliver the majority of long-term care in our country. NFCSP provides information and access to supportive services, respite care and counseling—all services proven to delay institutionalization of people with Alzheimer's disease and reduce costs to society and the government. Sequestration would cut NFCSP by \$12.6 million, hurting approximately 700,000 family caregivers supported annually and the older adults they care for, including many with Alzheimer's disease.

The historic National Plan to Address Alzheimer's Disease has done much to raise awareness and promote supportive services for individuals with dementia and their caregivers, while calling for a cure or prevention by 2025. Sequestration could erase these gains and take us off the path of eradicating this horrific disease by 2025, at a time when the incidence of the brain disorder is escalating at an unprecedented rate.

We, therefore, urge Congress to quickly solve this fiscal crisis and avoid devastating and unintended consequences to the most vulnerable individuals in our society.

If you have any questions or would like to discuss this issue directly, please contact Ian Kremer, Executive Director of LEAD, at [ikremer@leadcoalition.org](mailto:ikremer@leadcoalition.org) or 571-383-9916.

Respectfully,

Academy of Radiology Research  
Alliance for Aging Research  
Alzheimer's & Dementia Alliance of Wisconsin  
Alzheimer's Drug Discovery Foundation  
Alzheimer's Foundation of America  
Alzheimers North Carolina  
Alzheimer's Tennessee  
AMDA – Dedicated to Long Term Care Medicine™  
American Academy of Neurology  
American Association for Geriatric Psychiatry  
American Association for Long Term Care Nursing  
American Geriatrics Society  
American Life Science Pharmaceuticals, Inc.  
Assisted Living Federation of America  
Banner Health  
Beating Alzheimer's by Embracing Science  
BrightFocus Alzheimer's Disease Research  
Caregiver Action Network  
Cleveland Clinic Foundation  
Coalition for Imaging and Bioengineering Research  
Critical Path Institute – Coalition Against Major Disease

Cure Alzheimer's Fund  
Geoffrey Beene Foundation - Alzheimer's Initiative  
Georgetown University Medical Center Memory Disorders Program  
Gerontological Society of America  
Global Coalition on Aging  
Inspire  
Iona Senior Services  
Keep Memory Alive  
Latino Alzheimer's and Memory Disorders Alliance  
LeadingAge  
Linked Senior, Inc.  
Memory Enhancement Center of America, Inc.  
National Alliance for Caregiving  
National Association of States United for Aging and Disabilities  
National Caucus and Center on Black Aged, Inc. (NCBA)  
Neurotechnology Industry Organization  
New York Academy of Sciences  
Project Lifesaver International  
RetireSafe  
The Association for Frontotemporal Degeneration  
USAgainstAlzheimer's  
USF Health Byrd Alzheimer's Institute  
Vradenburg Foundation