

April 3, 2014

The Honorable Hal Rogers Chairman Committee on Appropriations H-307 The Capitol Washington, DC 20515

The Honorable Jack Kingston
Chairman
Committee on Appropriations
Subcommittee on Labor, HHS & Education
2358-B Rayburn House Office Building
Washington, DC 20515

The Honorable Nita Lowey
Ranking Member
Committee on Appropriations
1016 Longworth House Office Building
Washington, DC 20515

The Honorable Rosa DeLauro
Ranking Member
Committee on Appropriations
Subcommittee on Labor, HHS & Education
1001 Longworth House Office Building
Washington, DC 20515

Dear Chairman Rogers, Chairman Kingston, Ranking Member Lowey and Ranking Member DeLauro:

We thank Congress for recognizing and responding decisively in the FY 2014 Omnibus Budget to the challenges of Alzheimer's disease and related disorders including vascular, Lewy body or frontotemporal dementia. We applaud your determination to seize the enormous opportunities for America if we invest in the science, care and support required to overcome these challenges. Doing so is a national priority, an economic and budgetary necessity, a health and moral imperative.

As you assemble the Fiscal Year 2015 Labor, Health and Human Services, Education and Related Agencies Appropriations Act, we urge that you include \$32 billion for the National Institutes of Health (NIH). Of this amount, we request that you provide sufficient funding to support at least \$200 million in additional Alzheimer's disease and related disorders research to build upon the gains of recent years. We request also that you increase funding at the Administration for Community Living (ACL) by \$25 million for important caregiving and patient support programs.

We support the recommendation of leading scientists and of the Advisory Council on Alzheimer's Research, Care and Services that Congress and NIH ramp up Alzheimer's disease and related disorders research investments to a minimum of \$2 billion annually (FY 2014 investments are projected to remain below \$580 million). A minimum \$200 million increase in FY 2015 would be a bold and strategically imperative next step forward in addressing what now appears to be the third leading cause of death among all Americans.

Alzheimer's disease and related disorders currently impose enormous costs to our nation's health and prosperity, costs that are skyrocketing. <sup>ii</sup> The choice before our nation is not whether to pay for these diseases but whether we will emulate the investment strategies that have led to remarkable progress in fighting other leading causes of death such as cancer, HIV/AIDS and heart disease. Will we resolve to invest now in accelerated research and improved care, or will we surrender millions of deaths and trillions of dollars in healthcare costs because we acted too tentatively or too late?

Thanks to unanimous action by Congress, two years ago our nation adopted its first National Plan to Address Alzheimer's Disease. III To achieve the plan's first goal of preventing and treating Alzheimer's disease by 2025, the right and necessary next step is to include at least an additional \$200 million for Alzheimer's disease and related disorders research funding at the NIH above the estimated FY 2014 level. These dollars will support potentially groundbreaking research projects, particularly those aimed at better understanding the causes of Alzheimer's disease and related disorders and exploring ways to prevent or intervene at the earliest stages.

We also urge that you include at least \$25 million in new funding to support ACL's vital work to develop and disseminate evidence-based support services for Alzheimer's disease and related disorders patients and family caregivers. These programs are instrumental in achieving the plan's goals to enhance care quality, efficiency and expand supports. They provide needed respite to family caregivers and training in best practices to meet the many challenges of providing care to persons with dementia. Until an effective prevention, treatment or cure comes to market, families rely on these programs to protect their own well-being while helping their loved ones remain independent, in the community and free from more costly institutional settings.

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 <a href="mailto:ikremer@leadcoalition.org">ikremer@leadcoalition.org</a> or (571) 383-9916, with questions or for additional information.

Sincerely,

Abe's Garden

Activists Against Alzheimer's Network

African American Network Against Alzheimer's

Alliance for Aging Research

Alzheimers North Carolina

Alzheimer's & Dementia Alliance of Wisconsin

Alzheimer's Drug Discovery Foundation

Alzheimer's Foundation of America, LEAD Coalition co-convener

Alzheimer's Tennessee

AMDA-The Society for Post-Acute and Long-Term Care Medicine

American Academy of Neurology

American Association for Geriatric Psychiatry

American Association for Long Term Care Nursing

| American Geriatrics Society                                                               | Global Coalition on Aging                                                                     |
|-------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------|
| Assisted Living Federation of America                                                     | David Holtzman, MD (Washington<br>University School of Medicine,<br>Department of Neurology*) |
| Laura D. Baker, PhD (Wake Forest School of Medicine*)                                     |                                                                                               |
| Beating Alzheimer's by Embracing Science                                                  | Home Instead Senior Care                                                                      |
|                                                                                           | Inspire                                                                                       |
| James Brewer, M.D., Ph.D. (UC San<br>Diego and Alzheimer's Disease<br>Cooperative Study*) | Janssen Research & Development, LLC                                                           |
| • ,                                                                                       | Keep Memory Alive                                                                             |
| BrightFocus Foundation                                                                    | Lewy Body Dementia Association                                                                |
| Caregiver Action Network                                                                  | Linked Senior, Inc.                                                                           |
| Center for Alzheimer Research and<br>Treatment, Harvard Medical School                    | David G. Morgan, PhD (USF Health Byrd Alzheimer's Institute*)                                 |
| Cleveland Clinic Foundation                                                               | National Alliance for Caregiving                                                              |
| Cognition Therapeutics                                                                    | National Association of States United for                                                     |
| CorTechs Labs                                                                             | Aging and Disabilities                                                                        |
| Critical Path Institute                                                                   | National Down Syndrome Society                                                                |
| Jeffrey Cummings, MD, ScD (Cleveland<br>Clinic Lou Ruvo Center for Brain<br>Health*)      | National Hispanic Council on Aging                                                            |
|                                                                                           | National Task Group on Intellectual Disabilities and Dementia Practices                       |
| Cure Alzheimer's Fund                                                                     | Neurotechnology Industry Organization                                                         |
| Darrell K. Royal Fund for Alzheimer's Research                                            | New York Academy of Sciences                                                                  |
| Rachelle S. Doody, MD, PhD (Baylor                                                        | NYU Alzheimer's Disease Center                                                                |
| College of Medicine*)                                                                     | NYU Langone Center on Cognitive Neurology                                                     |
| Down Syndrome Research and<br>Treatment Foundation                                        | OWL-The Voice of Midlife and Older<br>Women                                                   |
| Forest Laboratories                                                                       | Pat Summitt Foundation                                                                        |
| Georgetown University Medical Center<br>Memory Disorders Program                          | Piramal Imaging                                                                               |
| Gerontological Society of America                                                         | Project Lifesaver International                                                               |

Research!America

Researchers Against Alzheimer's

Sage Bionetworks

Stephen Salloway, M.D., M.S. (The Warren Alpert Medical School of Brown University\*)

Reisa A. Sperling, MD, MMSc (Center for Alzheimer Research and Treatment, Harvard Medical School\*)

Taos Health Systems

The Association for Frontotemporal Degeneration

R. Scott Turner, MD, PhD (Georgetown University Memory Disorders Program\*)

USAgainstAlzheimer's, LEAD Coalition co-convener

USF Health Byrd Alzheimer's Institute

Volunteers of America

Washington University in St. Louis
Department of Neurology, the Knight
Alzheimer's Disease Research
Center, and the Hope Center for
Neurological Disorders

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.

<sup>&</sup>lt;sup>1</sup> http://www.neurology.org/content/early/2014/03/05/WNL.000000000000240

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

iii http://aspe.hhs.gov/daltcp/napa/NatlPlan2013.shtml

Leaders Engaged on Alzheimer's Disease (LEAD) is a diverse and growing national coalition of 65 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 disorders 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.