

September 17, 2014

The Honorable Barbara A. Mikulski Chairman Senate Committee on Appropriations United States Senate S. 128 The Capitol Washington, DC 20510

The Honorable Tom Harkin Chairman Senate Committee on Appropriations Subcommittee on Labor, HHS & Education 131 Dirksen Senate Office Building Washington, DC 20510

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

The Honorable Jack Kingston Chairman House Committee on Appropriations Subcommittee on Labor, HHS & Education 2358-B Rayburn House Office Building Washington, DC 20515 The Honorable Richard Shelby Ranking Member Senate Committee on Appropriations United States Senate S. 128 The Capitol Washington, DC 20510

The Honorable Jerry Moran Ranking Member Senate Committee on Appropriations Subcommittee on Labor, HHS & Education 156 Dirksen Senate Office Building Washington, DC 20510

The Honorable Nita Lowey Ranking Member House Committee on Appropriations 2358-B Rayburn House Office Building Washington, DC 20515

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

VIA ELECTRONIC DELIVERY

Dear Chairmen Mikulski, Harkin, Rogers and Kingston and Ranking Members Shelby, Moran, Lowey & DeLauro:

As you work to assemble a final Fiscal Year 2015 spending package, we urge you to include the \$100 million increase above Fiscal Year 2014 levels for the National Institute on Aging (NIA) that the Senate appropriations committee included in its draft Labor, HHS and Education bill. We also urge you to include within the final legislation the resources provided for in the Senate bill to advance Alzheimer's

disease and related dementias public health and caregiver support programs, and that you consider any potential opportunities to further increase any of these amounts.

You understand the immense impact – current and projected – that Alzheimer's disease and related dementias will have on our nation's health and finances. Providing this increase to the NIA will move us closer to the level of annual public research funding leading researchers have estimated is needed to maximize our chances of achieving the national goal of preventing and effectively treating Alzheimer's disease by 2025.¹ The NIA and the National Institutes of Health (NIH) – including other institutes such as the National Institute of Neurological Disorders and Stroke (NINDS), the National Institute of Biomedical Imaging and Bioengineering (NIBIB), and the National Institute of Mental Health (NIMH) – are supporting a number of promising research projects to: understand the genetic risk factors;" address the disproportionate impact on women," African Americans,^{iv} Hispanics,^v and persons with intellectual disabilities;^{vi} and pursue cuttingedge but costly and time consuming trials aimed at preventing or substantially slowing disease progression by administering treatments much earlier in the disease process. Including the additional \$100 million for the NIA that has been recommended by the Senate will provide additional resources to advance other meritorious Alzheimer's disease and related dementias research projects. This action will also demonstrate further the resolve behind our national goal, particularly at a time when other nations are looking to the United States for leadership and are beginning to take similar measures.

We understand the challenges you face in finalizing the FY 15 appropriations package. At the same time, we must recognize the current and projected health and financial threats posed by Alzheimer's disease and related dementias. Today our nation is spending more than \$150 billion annually in Medicare and Medicaid costs to care for upwards of five million persons impacted.^{viii} 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.^{ix} These figures will explode over the coming decades as our population ages, but an adequate commitment to research can help us prevent this future and move us closer to achieving our 2025 goal.^x

Thank you for considering our views and for your commitment to overcoming Alzheimer's disease and related disorders. Please contact Nick Manetto from USAgainstAlzheimer's at <u>Nicholas.Manetto@faegrebd.com</u> or (202) 312-7499, or Ian Kremer from the Leaders Engaged on Alzheimer's Disease (LEAD) Coalition^{xi} at <u>ikremer@leadcoalition.org</u> or (571) 383-9916, with questions or for additional information.

Sincerely,

Abe's Garden

Academy of Radiology Research

ActivistsAgainstAlzheimer's

- African American Network Against Alzheimer's
- Aging and Memory Disorder Programs, Howard University

Alliance for Aging Research

Alliance for Patient Access

Alzheimers North Carolina

- Alzheimer's & Dementia Alliance of Wisconsin
- 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 Long Term Care Nursing

- American Brain Coalition
- American Geriatrics Society

American Life Science Pharmaceuticals, Inc.

Assisted Living Federation of America

Laura D. Baker, PhD (Wake Forest School of Medicine*)

Banner Alzheimer's Institute

Blanchette Rockefeller Neurosciences Institute

B'nai B'rith International

Alice Bonner, PhD, RN (Northeastern University Bouve' College of Health Sciences*)

James Brewer, M.D., Ph.D. (UC San Diego and Alzheimer's Disease Cooperative Study*)

BrightFocus Foundation

Byrd Alzheimer's Institute, University of South Florida

Caregiver Action Network

Center for Alzheimer Research and Treatment, Harvard Medical School

Center for BrainHealth at The University of Texas at Dallas

Sandra Bond Chapman, PhD (Center for BrainHealth at The University of Texas at Dallas*)

ClergyAgainstAlzheimer's

Cleveland Clinic Foundation

Coalition for Imaging and Bioengineering Research **Cognition Therapeutics**

CorTechs Labs

Jeffrey Cummings, MD, ScD (Cleveland Clinic Lou Ruvo Center for Brain Health*)

Cure Alzheimer's Fund

Darrell K. Royal Fund for Alzheimer's Research

Department of Neurology, Washington University School of Medicine

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

Georgetown University Medical Center Memory Disorders Program

Gerontological Society of America

Lisa P. Gwyther, MSW, LCSW (Duke University Medical Center*)

Hearthstone Alzheimer Care

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

- Hospice Foundation of America
- Janssen Research & Development, LLC

Keep Memory Alive

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

Latino Alzheimer's and Memory Disorders Alliance

Lewy Body Dementia Association

LuMind Foundation (formerly Down Syndrome Research and Treatment Foundation)

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

National Alliance for Caregiving

National Association of Social Workers

National Association of States United for Aging and Disabilities National Caucus and Center on Black Aged, Inc. (NCBA)

National Certification Council for Activity Professionals

National Council on Aging

National Down Syndrome Society

National Hispanic Council On Aging (NHCOA)

National Task Group on Intellectual Disabilities and Dementia Practices

Neurotechnology Industry Organization

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

Pioneer Network

Piramal Imaging S.A.

Project Lifesaver International

Peter Reed, PhD (Sanford Center for Aging, University of Nevada Reno*) Research!America

ResearchersAgainstAlzheimer's

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*)

Rudolph Tanzi, PhD (Department of Neurology, MGH/Harvard Medical School*)

The Association for Frontotemporal Degeneration

THE GREEN HOUSE® Project

The I'm Still Here Foundation

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

USAgainstAlzheimer's, LEAD Coalition co-convener

Volunteers of America

Michael W. Weiner, MD (University of California San Francisco*)

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 http://aspe.hhs.gov/daltcp/napa/NatlPlan.pdf

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

ⁱⁱⁱ <u>http://www.alz.org/downloads/facts_figures_2014.pdf</u>

^{iv} <u>http://www.usagainstalzheimers.org/sites/default/files/USA2_AAN_CostsReport.pdf</u>

^v <u>http://www.nhcoa.org/wp-content/uploads/2013/05/NHCOA-Alzheimers-Executive-</u> <u>Summary.pdf</u>

^{vi} http://aadmd.org/sites/default/files/NTG_Thinker_Report.pdf

^{vii} <u>http://www.nia.nih.gov/alzheimers/publication/2012-2013-alzheimers-disease-progress-report/advancing-discovery-alzheimers#priorities</u>

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

^{ix} http://www.neurology.org/content/early/2014/03/05/WNL.000000000000240

* <u>http://www.alz.org/trajectory</u>

^{xi} <u>http://www.leadcoalition.org</u> 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.