

November 20, 2015

The Honorable Lamar Alexander Chairman Health, Education, Labor & Pensions Committee United States Senate 455 Dirksen Senate Office Building Washington, DC 20510 The Honorable Patty Murray Ranking Member Health, Education, Labor & Pensions Committee United States Senate 154 Russell Senate Office Building Washington, DC 20510

Via electronic delivery

Dear Chairman Alexander and Ranking Member Murray:

We thank you and your colleagues for the Senate Health, Education, Labor and Pensions (HELP) Committee's work to accelerate progress on the priorities of the National Plan to Address Alzheimer's Disease. In that spirit, we strongly encourage the HELP Committee to advance as soon as possible S. 2067, the Ensuring Useful Research Expenditures is Key for Alzheimer's (EUREKA) Act, to supplement, not supplant, other public and private sources of dementia research funding.

The EUREKA Act's key provisions reflect a keen understanding of dementia's enormous personal and societal toll. The Act places improved quality of life for people facing dementia today on equal footing with pursuit of scientific progress. The Act addresses dementia in all its causes including Alzheimer's disease, vascular disease, Lewy body disease, and frontotemporal degeneration. This is a time of great and deserved hope in dementia as Congressⁱⁱ and the National Institutes of Healthⁱⁱⁱ have begun to address chronic underfunding of research. The Act's focus on pay for success highlights that we need not only more research but better research, research that improves the lives of people living with dementia and caregivers today and that reduces or eliminates the risk of people having to live with dementia in the future.^{iv} We all know the public health, budgetary and macro-economic statistics about dementia. All too many people know first-hand the individual human toll, including the disproportionate impact on women, African Americans, Hispanics, and persons with intellectual disabilities (including those with Down syndrome). The EUREKA Act gives voice to the fundamental truth that dementia research needs greater urgency, greater innovation, and greater results.

We are among the leading proponents for an increased and sustained national commitment to research as well as for the development of tools and policies to accelerate the review of potential interventions and therapies by the Food and Drug Administration. The EUREKA Act would complement these and other efforts by authorizing prize competitions to pursue transformative solutions to some of the most vexing challenges hindering development of improved therapies and treatments, including care delivery mechanisms, for people with dementia and those who provide care.

Spurred by the potential power of the prize, the Act leverages this interest and potential reward by authorizing the National Institutes of Health to work with other relevant federal agencies and outside experts to develop EUREKA challenges. Challenges will be designed by experts in therapy development, healthcare innovation and prize competition sectors and can span a wide array of topics ranging from basic scientific breakthroughs through the development of innovative technologies to better assist people with dementia and caregivers. Each competition will stipulate specific desired goals and outcomes as well as metrics, and a panel of expert judges will evaluate all submissions to make recommendations on what, if any, awards should be made. The pay-for-success nature of the concept means that, aside from the costs associated with designing the competitions, public funds would be expended only upon achievement of success, creating a winning proposition given limited public funds. When successful, the EUREKA Act could serve as an evidence-based model for replicating the prize strategy in addressing other challenging diseases and conditions.

We urge you and your colleagues on the HELP Committee to review this legislation and to strongly consider advancing it in the 114th Congress. The issue appears to be particularly timely given the HELP Committee's extensive efforts to develop a forward-looking medical innovation agenda to accelerate development and delivery of therapies and treatments. With more than 5 million Americans living with dementia today, and a recent study indicating that Alzheimer's is the nation's most costly disease, this is the right time to implement the EUREKA Act's novel approach to therapeutic development and caregiving innovation.

Thank you for considering our views and for your commitment to overcoming Alzheimer's disease and other causes of dementia. Please contact Ian Kremer, executive director of Leaders Engaged on Alzheimer's Disease (the LEAD Coalition), i ikremer@leadcoalition.org or (571) 383-9916, with questions or for additional information.

Sincerely,

ACT on Alzheimer's

ActivistsAgainstAlzheimer's

African American Network Against Alzheimer's

Ageless Alliance

AgeneBio

Aging and Memory Disorder Programs, Howard University

Allergan

Alliance for Patient Access

Alzheimer's & Dementia Alliance of Wisconsin

Alzheimer's Drug Discovery Foundation

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

Alzheimers North Carolina

Alzheimer's Tennessee

American Academy of Neurology

American Association for Geriatric Psychiatry

American Association for Long
Term Care Nursing

American Federation for Aging Research (AFAR)

Argentum

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

Beating Alzheimer's by Embracing Science

Blanchette Rockefeller Neurosciences Institute

Soo Borson MD (University of Washington Schools of Medicine and Nursing*)

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

BrightFocus Alzheimer's Disease Research

Christopher M. Callahan, MD (Indiana University Center for Aging Research*)

Caregiver Action Network

Center for Elder Care and Advanced Illness, Altarum Institute

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

Cognition Therapeutics

CorTechs Labs

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

Darrell K. Royal Fund for Alzheimer's Research

Dementia Alliance International

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

Gary Epstein-Lubow, MD (Alpert Medical School of Brown University*)

Fujirebio

Sam Gandy, MD, PhD (Icahn School of Medicine at Mount Sinai*)

Joseph E. Gaugler, Ph.D. (School of Nursing, Center on Aging, University of Minnesota*)

Geoffrey Beene Foundation Alzheimer's Initiative

Daniel R. George, Ph.D, M.Sc (Penn State College of Medicine*)

Georgetown University Medical Center Memory Disorders Program

Georgia Institute on Aging

Gerontological Society of America

Laura N. Gitlin, PhD (Johns Hopkins School of Medicine*)

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

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

Home Instead Senior Care

Indiana University Center for Aging Research

Janssen R&D

Johns Hopkins School of Nursing Center for Innovative Care in Aging

Katherine S. Judge PhD (Cleveland State University*)

Keep Memory Alive

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

LatinosAgainstAlzheimer's

Lewy Body Dementia Association

Linked Senior, Inc

LuMind Research Down Syndrome Foundation

Mary Mittelman, DrPH (New York University Medical Center*)

David G. Morgan, PhD (USF Health Byrd Alzheimer's Institute*)

Mount Sinai Center for Cognitive Health

National Alliance for Caregiving

National Asian Pacific Center on Aging

National Certification Council for Activity Professionals

National Council for Behavioral Health

National Down Syndrome Society

National Hispanic Council On Aging (NHCOA)

National Task Group on Intellectual Disabilities and Dementia Practices

Neurocern

Neurotechnology Industry Organization

New York Academy of Sciences

NFL Neurological Center

Thomas O. Obisesan, MD, MPH (Howard University Hospital*)

OWL-The Voice of Women 40+

Pat Summitt Foundation

Planetree

Presence Care Project

Prevent Alzheimer's Disease 2020

ResearchersAgainstAlzheimer's

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

Second Wind Dreams, Inc./
Virtual Dementia Tour

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 Eden Alternative

The Evangelical Lutheran Good Samaritan Society

Geoffrey Tremont, Ph.D., ABPP-CN (Alpert Medical School of Brown University*)

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

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

Wisconsin Alzheimer's Institute

WomenAgainstAlzheimer'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/national-plan-address-alzheimer's-disease-2015-update

https://www.congress.gov/114/crpt/srpt74/CRPT-114srpt74.pdf "NIH-funded research is the only way to manage this disease in the future. Therefore, the Committee recommendation includes an increase of approximately \$350,000,000 for the National Institute on Aging, the NIH Institute with the primary responsibility for preventing, treating, and curing Alzheimer's disease."

https://www.nia.nih.gov/alzheimers/bypass-budget-fy2017

iv http://www.alz.org/trajectory

v http://www.neurology.org/content/early/2014/03/05/WNL.000000000000240

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

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

viii http://www.usagainstalzheimers.org/sites/default/files/USA2 AAN CostsReport.pdf

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 lssue Brief.pdf

x http://aadmd.org/sites/default/files/NTG Thinker Report.pdf

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 home and residential care providers, and biotechnology and pharmaceutical companies. The LEAD Coalition works collaboratively to focus the nation's strategic attention on dementia in all its causes -- including Alzheimer's disease, vascular disease, Lewy body disease, and frontotemporal degeneration -- 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.