LEAD
Leaders Engaged on Alzheimer's Disease

VIA ELECTRONIC DELIVERY

Re: Co-sponsorship for the Health Outcomes, Planning, and Education (HOPE) for Alzheimer's Act (S.709/H.R. 1507)

Dear Senator:

We applaud Congress and the Administration for recognizing and responding decisively to the challenges of Alzheimer's disease and related disorders through enactment of the National Alzheimer's Project Act (NAPA; Public Law 111-375) and implementation of the National Plan to Address Alzheimer's Disease (National Plan) that NAPA envisioned. In furtherance of the National Plan's goals, we write today to urge you to **cosponsor the Health Outcomes, Planning, and Education (HOPE) for Alzheimer's Act (S.709/H.R. 1507)**.[1] If you a co-sponsor, thank you and we urge you to encourage your colleagues to become co-sponsors. For more information about becoming a co-sponsor, please contact Alex Sheff in Senator Stabenow's office (alex_sheff@stabenow.senate.gov) or Priscilla Hanley from Senator Collins' Aging Committee staff (Priscilla_Hanley@aging.senate.gov).

More than 5 million Americans have Alzheimer's disease and millions more have vascular, Lewy body or frontotemporal dementia. Many do not get diagnosed or know all of the treatment options available to them. The National Plan calls for ensuring timely and accurate diagnosis, enhancing care quality and efficiency, and educating and supporting people with Alzheimer's disease and their families. The Advisory Council on Alzheimer's Research, Care, and Services specifically recommended that Congress and CMS redesign Medicare coverage and reimbursement to encourage appropriate diagnosis of Alzheimer's disease and provide care planning to diagnosed individuals and their caregivers. The HOPE for Alzheimer's Act would ensure earlier diagnosis and equip individuals with Alzheimer's disease and their families with better tools to cope with this heartbreaking disease. Doing so is a national priority, an economic and budgetary necessity, a health and moral imperative.

Nearly everything medical professionals, patients and family caregivers do

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[1] Under Section 3.(a)(3)(A) of the HOPE for Alzheimer's Act, "the term 'Alzheimer's disease' means Alzheimer's disease and related dementias"

depends on a timely and accurate diagnosis. Patients and families want, deserve and need to know the cause of cognitive impairment. A timely, accurate and clearly communicated diagnosis reduces disease-related stigma; allows the family to build a care team and seek out education and support services; provides access to approved medications and behavioral interventions; offers an opportunity for timely development of advance directives, financial planning and declaration of end-of-life wishes; and facilitates clinical trial enrollment.

An accurate and timely diagnosis, medical record documentation, and access to care planning leads to better outcomes for individuals with Alzheimer's disease and other dementias as well as their caregivers. Unfortunately, as many as half of the more than 5 million Americans with Alzheimer's disease have never received a formal diagnosis, and a study in the Journal of General Internal Medicine indicated only 19 percent of people over age 65 with dementia had a diagnosis recorded in their medical record. Special populations -- including people with lifelong disabilities, younger onset dementia, and persons from minority groups – often face additional barriers to early detection and diagnosis.

An accurate diagnosis and knowledge of all of an individual's conditions allows for better disease management and more efficient utilization of medical resources, including reducing complications and the number of costly emergency room visits and hospitalizations. A study in the journal Neurology found that six counseling sessions for caregivers after an Alzheimer's diagnosis delayed nursing home placement for those with Alzheimer's disease by almost one and a half years. The potential for reduced costs is of increasing importance because the total cost of care for those with Alzheimer's disease is increasing rapidly, and will rise from $203 billion in 2013 to $1.2 trillion by 2050.

The HOPE for Alzheimer's Act will help ensure that individuals receive an appropriate diagnosis, and that they and their family get critical information about the disease and available care options, which leads to better outcomes. The bill would combine the existing Medicare benefits for diagnosis and care planning into a single package of services that includes: 1) a comprehensive clinical diagnostic evaluation for Alzheimer's disease; 2) care planning services to provide newly-diagnosed individuals, their personal representative, or family caregivers information about options for treatment and support; and 3) documentation of both the diagnosis and any care planning services in the beneficiary's medical record.

According to a June, 2013 report from Research!America, an overwhelming majority of Americans say they would participate in a clinical trial if it were recommended by their doctor, but less than a quarter of respondents reported healthcare professionals even raising the subject. The HOPE for Alzheimer's Act would encourage not only diagnosis and documentation in patient records but also foster communication of the diagnosis between physicians and patients so that diagnosed individuals would know they could be eligible to participate in relevant clinical trials.

As we work to improve available treatments for Alzheimer's disease, we must ensure that the millions of Americans with Alzheimer's disease and other dementias receive appropriate care today. Please become a co-sponsor of the HOPE for Alzheimer's Act.

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 ikremer@leadcoalition.org or (571) 383- 9916, with questions or for additional information.

Sincerely,

Alzheimer's & Dementia Alliance of Wisconsin

Alzheimer's Foundation of America

Alzheimers North Carolina

Alzheimer's Tennessee

AMDA – Dedicated to Long Term Care Medicine TM

American Academy of Neurology

American Association for Geriatric Psychiatry

American Association for Long Term Care Nursing

Assisted Living Federation of America

Banner Alzheimer's Institute

Beating Alzheimer's by Embracing Science

BrightFocus Alzheimer's Disease Research

Caregiver Action Network

Center for Alzheimer Research and Treatment, Harvard Medical School

Cleveland Clinic Foundation

Cortica Neurosciences, Inc.

Critical Path Institute/Coalition Against Major Diseases

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

Cure Alzheimer's Fund

Dr. Michael Devous Sr. (University of Texas Southwestern Medical Center*)

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

Georgetown University Medical Center Memory Disorders Program

Gerontological Society of America

Global Coalition on Aging

Howard University, Aging and Memory Disorder Programs

Janssen Alzheimer Immunotherapy

Latino Alzheimer's and Memory Disorders Alliance

Lewy Body Dementia Association

Linked Senior, Inc.

Kostas Lyketsos, M.D., M.H.S. (Johns Hopkins Memory and Alzheimer's Treatment Center*)

Dave Morgan, PhD (USF Health Byrd Alzheimer's Institute*)

National Alliance for Caregiving

National Association of States United for Aging and Disabilities

National Down Syndrome Society

National Task Group on Intellectual Disabilities and Dementia Practices

Neurotechnology Industry Organization

New York Academy of Sciences

NYU Langone Comprehensive Center on Brain Aging/NYU Langone Silberstein Alzheimer's Institute

NYU Alzheimer's Disease Center

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

OWL-The Voice of Midlife and Older Women

Piramal Imaging

Project Lifesaver International

RemeGenix, Inc.

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*)

The Association for Frontotemporal Degeneration

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

USAgainstAlzheimer's

USF Health Byrd Alzheimer's Institute

Volunteers of America

Washington University School of Medicine, Department of Neurology (St. Louis, Missouri)

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

WomenAgainstAlzheimer's

Wooten Laboratory for Alzheimer's and Neurodegenerative Diseases Research

* Affiliations of individual researchers are for identification purposes only and do not necessarily represent the endorsement of the affiliated institution.

[Leaders Engaged on Alzheimer's Disease](#) (LEAD) is a diverse and growing coalition of 61 member organizations including patient advocacy and voluntary health non-profits, philanthropies and foundations, trade and professional associations, academic research and clinical institutions, and 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 care and support, detection and diagnosis, and research leading to prevention, effective treatment and eventual cure. One or more participants may have a financial interest in the subjects addressed.