



October 22, 2013

The Honorable Robert Casey, Jr.  
393 Russell Senate Office Building  
Washington, D.C. 20510

The Honorable Ander Crenshaw  
440 Cannon House Office Building  
Washington, DC 20515

The Honorable Richard Burr  
217 Russell Senate Office Building  
Washington, DC 20510

The Honorable Chris Van Hollen  
1707 Longworth House Office Building  
Washington, DC 20515

The Honorable Cathy McMorris Rodgers  
203 Cannon House Office Building  
Washington, DC 20515

The Honorable Pete Sessions  
2233 Rayburn House Office Building  
Washington, DC 20515-4332

**VIA ELECTRONIC DELIVERY**

Dear Senator Casey, Senator Burr, Congressman Crenshaw, Congressman Van Hollen, Congresswoman Cathy McMorris Rodgers and Congressman Sessions:

**Thank you for introducing the Achieving a Better Life Experience (ABLE) Act of 2013 (S. 313/H.R.647). We look forward to working with you to support enactment of the ABLE Act this year.**

Today, over five million Americans have Alzheimer's disease -- and millions more have vascular, Lewy body or frontotemporal dementia. It is expected that 13 million or more Americans will have Alzheimer's disease by 2050, barring a major scientific breakthrough in the near-term. For many individuals and families facing the enormous financial toll of a typically decade-long battle with Alzheimer's disease or a related dementia,<sup>i</sup> the ABLE Act will provide an important tool to avoid impoverishment and dependence on public assistance programs. This is consistent the intent of the National Alzheimer's Project Act (Public Law 111-375) and the resulting National Plan to Address Alzheimer's Disease Goal 3, Strategy 3.C: Assist Families in Planning for Future Care Needs<sup>ii</sup>.

The ABLE Act will allow individuals with physical, intellectual or cognitive disabilities and their families to save their private funds for the future just like every other American. The ABLE Act builds upon a highly successful tax-deferred education savings platform to begin addressing the challenges of paying for quality long-term care services by establishing a new subsection within Section 529 of the Internal Revenue Code. Individuals with disabilities would be permitted to establish ABLE accounts into which they and others could make tax-deferred contributions. ABLE account funds then could be used for essential expenses including medical and dental care, community-based supports, assistive technology, housing and transportation. Such qualified expenditures would supplement, but not supplant, benefits provided through private insurance, Medicaid, Supplemental Security Income (SSI), the beneficiary's employment, and other sources. The legislation also contains Medicaid fraud protection against abuse and a Medicaid payback provision when the beneficiary passes away.

Currently, individuals with disabilities often must rely on services through Medicaid and income supports through SSI both of which impose significant limitations on the amount of assets they can maintain. Functionally, these limits impose unwelcome and counter-productive barriers to employment, independent living, and economic self-sufficiency. The ABLE Act frees people with disabilities to invest in their own future without fear of becoming ineligible for Medicaid and SSI. Equally important, the legislation will allow family and loved ones of beneficiaries diagnosed with Alzheimer's disease or a related dementia to contribute to accounts that can be used to pay for the diagnosed individual's long-term care needs.

**We appreciate your leadership and are committed to helping you deliver the ABLE Act to the President's desk before the end of 2013.**

Please contact Ian Kremer from the Leaders Engaged on Alzheimer's Disease (LEAD)<sup>iii</sup> Coalition ([ikremer@leadcoalition.org](mailto:ikremer@leadcoalition.org) or 571-383- 9916) or Sara Weir from the National Down Syndrome Society ([sweir@ndss.org](mailto:sweir@ndss.org) or 202-465-3222) with questions or for additional information.

Sincerely,

Abe's Garden

Alliance for Aging Research

Alzheimers North Carolina

Alzheimer's & Dementia Alliance of Wisconsin

Alzheimer's Foundation of America

Alzheimer's Tennessee

American Association for Geriatric Psychiatry  
American Association for Long Term Care Nursing  
Assisted Living Federation of America  
Laura D. Baker, PhD (Wake Forest School of Medicine\*)  
Banner Alzheimer's Institute  
BrightFocus Alzheimer's Disease Research  
Caregiver Action Network  
Cleveland Clinic Foundation  
Jeffrey Cummings, MD, ScD (Cleveland Clinic Lou Ruvo Center for Brain Health\*)  
Darrell K. Royal Fund for Alzheimer's Research  
Rachelle S. Doody, MD, PhD (Baylor College of Medicine\*)  
Geoffrey Beene Foundation - Alzheimer's Initiative  
Georgetown University Medical Center Memory Disorders Program  
Gerontological Society of America  
Global Coalition on Aging  
David Holtzman, MD (Washington University School of Medicine, Department of Neurology\*)  
Inspire  
Keep Memory Alive  
Latino Alzheimer's and Memory Disorders Alliance  
Linked Senior, Inc.  
Dave Morgan, PhD (USF Health Byrd Alzheimer's Institute\*)  
National Alliance for Caregiving  
National Caucus and Center on Black Aged, Inc.  
National Down Syndrome Society  
National Task Group on Intellectual Disabilities and Dementia Practices  
New York Academy of Sciences  
NYU Langone Comprehensive Center on Brain Aging/NYU Langone Silberstein Alzheimer's Institute  
NYU Alzheimer's Disease Center  
OWL-The Voice of Midlife and Older Women  
Piramal Imaging

ResearchersAgainstAlzheimer's

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\*)

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

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<sup>i</sup> <http://www.nejm.org/doi/pdf/10.1056/NEJMsa1204629>

<sup>ii</sup> <http://aspe.hhs.gov/daltcp/napa/NatlPlan2013.shtml#strategy3.C>

<sup>iii</sup> [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.