



May 18, 2015

The Honorable Sylvia Matthews Burwell  
Secretary  
The U.S. Department of Health and Human Services  
200 Independence Avenue, S.W.  
Washington, D.C. 20201

Francis Collins, M.D., Ph.D.  
Director  
National Institutes of Health  
Building 1  
9000 Rockville Pike  
Bethesda, Maryland 20892

Kathy Greenlee  
Administrator, Administration for Community Living  
Assistant Secretary for Aging  
U.S. Department of Health and Human Services  
One Massachusetts Avenue, NW  
Washington, DC 20001

Andy Slavitt  
Acting Administrator  
Centers for Medicare & Medicaid Services  
7500 Security Boulevard  
Baltimore, MD 21244

***via electronic delivery***

Dear Secretary Burwell, Director Collins, Administrator Greenlee and Acting Administrator Slavitt:

**We urge the U.S. Department of Health and Human Services (DHHS) -- through the leadership of the National Institutes of Health (NIH), the Administration for Community Living (ACL), and the Centers for Medicare & Medicaid Services -- to organize a *National Research Summit on Care and Services for Persons with Alzheimer's Disease and Related Dementias* to be held in the first half of 2016. We will be your active private sector partners in bringing the summit to fruition and advancing recommendations emerging from the summit.**

DHHS spends over \$150 billion annually in Medicare and Medicaid costs to care for people living with Alzheimer's disease and related dementias.<sup>i</sup> Alzheimer's disease alone contributes to the deaths of approximately 500,000 Americans each year, making it the third leading cause of death in the United States.<sup>ii</sup> These figures will explode over the coming decades as our population ages<sup>iii</sup> and as more people receive timely and accurate detection and diagnosis.<sup>iv</sup> While the biomedical research community invests in seeking disease-modifying interventions, over 5 million Americans living with dementia and 15 million caregivers need care and services research to maximize the return on public and private investments aimed at their immediate and future quality of life needs. We owe it to the taxpayers, to the research community and – most of all – to people living with, or at risk of, Alzheimer's disease and related dementias to apply research resources in the most efficient, translatable, scalable, and ethically consistent manner possible. The summit we propose would examine the current state of research, identify gaps, and recommend research pathways to improve care and services until the day when biomedical research eliminates dementia altogether.

To date, NIH has led three excellent summits focused primarily on biomedical research -- May 2012,<sup>v</sup> May 2013,<sup>vi</sup> and February 2015<sup>vii</sup> – that resulted in valuable information to help DHHS, NIH, and the Advisory Council on Alzheimer's Research, Care, and Services (**Advisory Council**) identify and update research priorities for the National Plan to Address Alzheimer's Disease (**National Plan**),<sup>viii</sup> particularly with respect to Goal 1, *Prevent and Effectively Treat Alzheimer's Disease by 2025*. While each of these summits included some presentations and discussion about research on care and services, we believe it is time for a first summit focusing primarily on care and services research intended to improve the day-to-day functioning and quality of life of persons with Alzheimer's disease and related dementias.

The *National Research Summit on Care and Services for Persons with Alzheimer's Disease and Related Dementias* would inform the care and services field and assist DHHS, NIH, ACL, CMS and other agencies, and the Advisory Council in setting relevant priorities and milestones for the National Plan. In particular, the summit would inform the development of research priorities related to Goal 2, *Enhance Care Quality and Efficiency*, Goal 3, *Expand Supports for People with Alzheimer's Disease and their Families*, and some components of Goal 4, *Enhance Public Awareness and Engagement*.

A rapidly growing body of research conducted in the United States and abroad has identified approaches to care and services that result in positive outcomes for people living with Alzheimer's disease and related dementias, reduced behavioral symptoms, and decreased detrimental effects of caregiving for family members and others who provide care and support. Still, significant research gaps remain in what we need to know to improve the lived experience of Alzheimer's disease and other dementias for people with the conditions and their caregivers. To date, there has not been a national conference in the United States to assess what we know now, identify important gaps, and establish a research agenda for the future, including translation research to determine whether care and services that have been shown to be effective in research settings can be effectively implemented and scaled in various settings outside the research environment.

We hope that NIA and NINDS would be involved in planning the *National Research Summit on Care and Services for Persons with Alzheimer's Disease and Related Dementias* given their strong record with the previous three summits and given that they fund care and services research in addition to biomedical research. We also would encourage other NIH

institutes to be involved in planning the summit, including: the National Institute on Mental Health (NIMH), the National Institute on Nursing Research (NINR), and the National Institute of Child Health and Development (NICHD). It is equally important to involve other DHHS agencies that fund dementia-related care and services research and that pay for care and services delivery, in particular: the Centers for Medicare and Medicaid Services (CMS), the Administration for Community Living (ACL), the Agency for Healthcare Research and Quality (AHRQ), the Centers for Disease Control and Prevention (CDC), the Health Resources and Services Administration (HRSA), the Indian Health Service (IHS), the Office of the Assistant Secretary for Planning and Evaluation (ASPE), the Administration on Intellectual and Developmental Disabilities (AIDD), and the Substance Abuse and Mental Health Services Administration (SAMHSA). Outside DHHS, the Department of Veterans Affairs (VA), and the Department of Defense (DOD) fund research on dementia care and services and should be involved in planning the summit. Other federal agencies, including the Department of Transportation (DOT), the Department of Justice (DOJ), the Consumer Financial Protection Bureau (CFPB), the Department of Housing and Urban Development (HUD), the Departments of Labor (DOL) and the Department of Education (DOE) fund, or could fund, dementia care and services research and could be involved in planning the summit.

The goal should be to establish a prioritized and milestone driven national research agenda on care and services to improve day-to-day functioning and quality of life for people with Alzheimer's disease and related dementias and reduce the negative effects of caregiving on families and other caregivers. Relevant research conducted in the United States and other countries should be included, and input about needed research should be sought from state and local government agencies, advocacy organizations, professional and provider organizations, researchers, and other stakeholders.

The summit should address current knowledge and research needs with respect to similarities and differences in effective care and services for the diverse array of individuals with dementia and their family and other caregivers, including:

- Individuals who have dementia caused by Alzheimer's disease, vascular disease, Lewy body dementia, Parkinson's disease, frontotemporal dementias, and mixed causes;
- Individuals with Down syndrome and other intellectual disabilities who develop Alzheimer's disease or other dementias;
- Individuals of different ages and at different stages of dementia;
- Individuals of various races, ethnicities, cultures, and socioeconomic status.

The summit should address the full range of available and needed research on care and services across all settings, including research to identify and specify problems; design and pilot test possible approaches to resolve the identified problems; rigorously evaluate promising interventions; and further test interventions that have been found to work in research settings as they are translated and scaled into non-research settings.

**We hope DHHS, NIH, ACL and CMS will support and take the lead in organizing the *National Summit on Care and Services for Persons with Alzheimer's Disease and Related Dementias* and encourage the other relevant federal government agencies to join in planning the summit. We hope that the planning process will begin soon and that the summit will be held within the next 15 months. We will be your active private**

**sector partners planning the summit, bringing it to fruition, and advancing recommendations emerging from the summit.**

Thank you for considering our views and for your commitment to overcoming Alzheimer's disease and related dementias. Please contact Ian Kremer, executive director of Leaders Engaged on Alzheimer's Disease (the LEAD Coalition),<sup>ix</sup> [ikremer@leadcoalition.org](mailto:ikremer@leadcoalition.org) or (571) 383-9916, with questions or for additional information.

Sincerely,

Abe's Garden	Assisted Living Federation of America
Actavis	Association of Population Centers
ACT on Alzheimer's	Association of Professional Chaplains
ActivistsAgainstAlzheimer's	Laura D. Baker, PhD (Wake Forest School of Medicine*)
Advancing Excellence in Long-Term Care Collaborative	Banner Alzheimer's Institute
African American Network Against Alzheimer's	David M. Bass, PhD (Benjamin Rose Institute on Aging*)
Aging and Memory Disorder Programs, Howard University	Beating Alzheimer's by Embracing Science
Alliance for Aging Research	Benjamin Rose Institute on Aging
Alliance for Home Health Quality & Innovation	Biogen Idec
Alzheimer's & Dementia Alliance of Wisconsin	Biotechnology Industry Organization (BIO)
Alzheimer's Foundation of America, LEAD Coalition co-convener	Blanchette Rockefeller Neurosciences Institute
Alzheimers North Carolina	James Brewer, M.D., Ph.D. (UC San Diego and Alzheimer's Disease Cooperative Study*)
Alzheimer's Tennessee	BrightFocus Alzheimer's Disease Research
AMDA – The Society for Post-Acute and Long-Term Care Medicine	Brown University Center for Long-Term Care Quality & Innovation
American Association for Geriatric Psychiatry	Christopher M. Callahan, MD (Indiana University Center for Aging Research*)
American Association for Long Term Care Nursing	Caregiver Action Network
American Federation for Aging Research (AFAR)	CCAL-Advancing Person-Centered Living
American Health Care Association	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

Center to Advance Palliative Care

Sandra Bond Chapman, PhD (Center for  
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Dallas\*)

ClergyAgainstAlzheimer's

Cleveland Clinic Foundation

Cognition Therapeutics

CorTechs Labs

Suzanne Craft, PhD (Wake Forest School of  
Medicine\*)

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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Sam Gandy, MD, PhD (Icahn School of  
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Geoffrey Beene Foundation Alzheimer's  
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Georgia Institute on Aging

Daniel R. George, Ph.D, M.Sc (Penn State  
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GE

Georgetown University Medical Center  
Memory Disorders Program

Gerontological Society of America

Laura N. Gitlin, PhD (Johns Hopkins School  
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Global Coalition on Aging

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

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

Home Instead Senior Care

Hospice and Palliative Nurses Association

Hospice Foundation of America

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  
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Keep Memory Alive

Diana R Kerwin, MD (Texas Alzheimer's  
and Memory Disorders\*)

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

LatinosAgainstAlzheimer's

Latino Alzheimer's and Memory Disorders  
Alliance

LeadingAge

Lewy Body Dementia Association	Neurocern
Linked Senior, Inc	Neurotechnology Industry Organization
LuMind Research Down Syndrome Foundation	New York Academy of Sciences
Merck	NFL Neurological Center
Mary Mittelman, DrPH (New York University Medical Center*)	NYU Alzheimer's Disease Center
David G. Morgan, PhD (USF Health Byrd Alzheimer's Institute*)	NYU Langone Center on Cognitive Neurology
Mount Sinai Center for Cognitive Health	Thomas O. Obisesan, MD, MPH (Howard University Hospital*)
National Alliance for Caregiving	OWL-The Voice of Women 40+
National Association of Activity Professionals	Pat Summitt Foundation
National Association of Area Agencies on Aging	Pfizer, Inc.
National Association of Chronic Disease Directors	Pioneer Network
National Association of Nutrition and Aging Services Programs (NANASP)	Piramal Imaging S.A.
National Association of States United for Aging and Disabilities	Planetree
National Center for Assisted Living	Population Association of America
National Certification Council for Activity Professionals	Presence Care Project
National Coalition for Hospice and Palliative Care	Project Lifesaver International
National Committee to Preserve Social Security and Medicare	Peter Reed, PhD (Sanford Center for Aging, University of Nevada Reno*)
National Council for Behavioral Health	Research!America
National Down Syndrome Society	ResearchersAgainstAlzheimer's
National Hispanic Council On Aging (NHCOA)	Sage Bionetworks
National Task Group on Intellectual Disabilities and Dementia Practices	Stephen Salloway, M.D., M.S. (The Warren Alpert Medical School of Brown University*)
	Second Wind Dreams, Inc./ Virtual Dementia Tour
	Social Work Hospice and Palliative Care Network
	Reisa A. Sperling, MD, MMSc (Center for Alzheimer Research and Treatment, Harvard Medical School*)

Taos Health Systems

The Association for  
Frontotemporal Degeneration

The Eden Alternative

The Evangelical Lutheran Good Samaritan  
Society

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USAgainstAlzheimer's, LEAD Coalition co-  
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USF Health Byrd Alzheimer's Institute

Volunteers of America

Peter J. Whitehouse, MD, PhD  
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Nancy Wilson, MA LCSW (Baylor College of  
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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.*

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

<sup>ii</sup> <http://www.neurology.org/content/early/2014/03/05/WNL.0000000000000240>

<sup>iii</sup> [https://www.alz.org/facts/downloads/facts\\_figures\\_2015.pdf](https://www.alz.org/facts/downloads/facts_figures_2015.pdf)

<sup>iv</sup> <https://www.geron.org/programs-services/alliances-and-multi-stakeholder-collaborations/workgroup-on-cognitive-impairment-detection-and-earlier-diagnosis>

<sup>v</sup> <http://www.nia.nih.gov/about/events/2012/alzheimers-disease-research-summit-2012-path-treatment-and-prevention>

<sup>vi</sup> <http://www.ninds.nih.gov/funding/areas/neurodegeneration/workshops/adrd2013/>

<sup>vii</sup> <http://www.nia.nih.gov/about/events/2014/alzheimers-disease-research-summit-2015>

<sup>viii</sup> <http://aspe.hhs.gov/daltcp/napa/#Plan>

<sup>ix</sup> <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 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.