



February 13, 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

*via electronic delivery*

Dear Secretary Burwell:

**We write to urge you to attend the World Health Organization's (WHO) First Ministerial Meeting on Dementia, on March 16 and 17, in Geneva, Switzerland.**

There is a growing and globally integrating effort to address Alzheimer's disease and related dementias. The United States has unparalleled capacity to lead the global alliance and strengthen the opportunities to achieve or surpass our national goal – embraced and adopted in 2013 by the G8 -- of preventing and effectively treating Alzheimer's disease and related dementias by 2025.<sup>i</sup> The WHO First Ministerial Meeting on Dementia will shape the global agenda in 2015 and beyond; your direct participation is an essential next step in providing American leadership, vision and resolve.

WHO is inviting the health ministers from more than 60 countries. Health ministers are being invited rather than science or service program leaders precisely because Alzheimer's disease and related dementias require comprehensive and crosscutting action. Scientists can lead science summits and program experts can lead social policy summits. Health ministers must lead a ministerial meeting on dementia. Your participation will send a powerful message both to the international community and to domestic stakeholders including across HHS, Congress and – most important – the millions of Americans living with Alzheimer's disease and related dementias and their loved ones.

The WHO First Ministerial Meeting on Dementia will set the framework for addressing 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 people living with Alzheimer's disease and related dementias.<sup>ii</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>iii</sup> These figures will explode over the coming decades as our population ages, but a modernized and more robust

research enterprise can help us prevent this catastrophe and move us closer to achieving our 2025 goal.<sup>iv</sup>

Under your leadership, HHS continues to overcome enormous obstacles and increase prioritization of Alzheimer's disease and related dementias. Assistant Secretary for Planning and Evaluation Dr. Richard Frank has encouraged a no-holds-barred environment for publicly appointed members of the Advisory Council on Alzheimer's Research, Care, and Services to generate for your consideration their most thoughtful and catalytic recommendations for the National Plan to Address Alzheimer's Disease; for example, this year's work has included a heightened focus on improving care for people with advanced dementia.<sup>v</sup> Food and Drug Administration (FDA) Commissioner Dr. Margaret Hamburg has worked tirelessly and effectively to encourage new avenues of research with substantially clarified paths to regulatory approval. National Institutes of Health Director Dr. Francis Collins has moved mountains to identify additional resources, new public-private partnerships, and a culture of urgency. The National Institute on Aging (NIA) and other NIH institutes -- such as the National Institute of Neurological Disorders and Stroke, the National Institute of Biomedical Imaging and Bioengineering, the National Institute of Mental Health and the National Institute of Child Health and Human Development -- are supporting a number of promising research projects to: understand the genetic risk factors;<sup>vi</sup> address the disproportionate impact on women,<sup>vii</sup> African Americans,<sup>viii</sup> Hispanics,<sup>ix</sup> and persons with intellectual disabilities;<sup>x</sup> and pursue cutting-edge but costly and time consuming trials aimed at preventing or substantially slowing disease progression by administering treatments much earlier in the disease process.<sup>xi</sup> Your attendance at the WHO First Ministerial Meeting on Dementia would highlight these and other examples of America's capacity and determination to lead the global effort to overcome Alzheimer's disease and related disorders.

We stand ready to assist you in any way to prepare for the WHO First Ministerial Meeting on Dementia with briefing documents or any other information and resources you may need.

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

Sincerely,

Abe's Garden

Academy of Radiology Research

Actavis

ActivistsAgainstAlzheimer's

African American Network Against  
Alzheimer's

Aging and Memory Disorder Programs,  
Howard University

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

AMDA – The Society for Post-Acute and  
Long-Term Care Medicine

American Academy of Neurology

American Association for Long Term Care  
Nursing

American Federation for Aging Research  
(AFAR)

Assisted Living Federation of America

Association of Population Centers

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

Beating Alzheimer's by Embracing Science

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

Caregiver Action Network

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 BrainHealth at The University of Texas at Dallas\*)

ClergyAgainstAlzheimer's

Cleveland Clinic Foundation

Coalition for Imaging and Bioengineering Research

Cognition Therapeutics

CorTechs Labs

Critical Path Institute

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\*)

Eli Lilly and Company

Geoffrey Beene Foundation Alzheimer's Initiative

Georgetown University Medical Center Memory Disorders Program

Gerontological Society of America

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

Home Instead Senior Care

Iona Senior Services

Janssen R&D

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

League of United Latin American Citizens

Lewy Body Dementia Association

LinkedSenior

LuMind Foundation (formerly Down Syndrome Research and Treatment Foundation)

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

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

National Alliance for Caregiving

National Association of Chronic Disease Directors

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 Down Syndrome Society  
National Hispanic Council on Aging  
National Task Group on Intellectual Disabilities and Dementia Practices  
Neurocern  
Neurotechnology Industry Organization  
New York Academy of Sciences  
NYU Langone Center on Cognitive Neurology  
NYU Alzheimer's Disease Center  
Thomas O. Obisesan, MD, MPH (Howard University Hospital\*)  
OWL-The Voice of Women 40+  
Pat Summitt Foundation  
Pioneer Network  
Piramal Imaging S.A.  
Population Association of America  
Presence Care Project  
Prevent Alzheimer's Disease 2020  
Research!America  
ResearchersAgainstAlzheimer's  
Sage Bionetworks

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\*)  
Taos Health Systems  
The Association for Frontotemporal Degeneration  
The Eden Alternative  
The Evangelical Lutheran Good Samaritan Society  
THE GREEN HOUSE® Project  
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  
Women Against Alzheimer'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://aspe.hhs.gov/daltcp/napa/NatIPlan.pdf>
- <sup>ii</sup> <http://www.nejm.org/doi/pdf/10.1056/NEJMsa1204629>
- <sup>iii</sup> <http://www.neurology.org/content/early/2014/03/05/WNL.0000000000000240>
- <sup>iv</sup> <http://www.alz.org/trajectory>
- <sup>v</sup> <http://aspe.hhs.gov/daltcp/napa/012615/Mtg15-Slides4.pdf>
- <sup>vi</sup> <http://www.nia.nih.gov/alzheimers/publication/2012-2013-alzheimers-disease-progress-report/genetics-alzheimers-disease>
- <sup>vii</sup> [http://www.alz.org/downloads/facts\\_figures\\_2014.pdf](http://www.alz.org/downloads/facts_figures_2014.pdf)
- <sup>viii</sup> [http://www.usagainstalzheimers.org/sites/default/files/USA2\\_AAN\\_CostsReport.pdf](http://www.usagainstalzheimers.org/sites/default/files/USA2_AAN_CostsReport.pdf)
- <sup>ix</sup> <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\\_Issue\\_Brief.pdf](http://www.usagainstalzheimers.org/sites/all/themes/alzheimers_networks/files/LatinosAgainstAlzheimers_Issue_Brief.pdf)
- <sup>x</sup> [http://aadmd.org/sites/default/files/NTG\\_Thinker\\_Report.pdf](http://aadmd.org/sites/default/files/NTG_Thinker_Report.pdf)
- <sup>xi</sup> <http://www.nia.nih.gov/alzheimers/publication/2012-2013-alzheimers-disease-progress-report/advancing-discovery-alzheimers#priorities>
- <sup>xii</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 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.