



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-convenor

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/NatlPlan.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.