



August 16, 2015

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

***via electronic submission***

***Request for Information (RFI): Inviting Comments and Suggestions on a Framework for the NIH-wide Strategic Plan***

***Notice Number: NOT-OD-15-118***

Dear Director Collins:

We urge that the National Institutes of Health include in its strategic plan framework:

- Explicit recognition that disease burden includes the number of people with the disease and informal caregivers, symptomatic duration and intensity, economic and budgetary impact, and financial cost to affected families;
- Need to develop more accelerated capacity to uptake congressional funding increases (e.g. proposed 50<sup>i</sup> to 60%<sup>ii</sup> FY 16 increase in dementia research funding);
- Prioritization of developing evidence-based interventions that align with population-based health care delivery, that improve care of people living with dementia, and that protect the physical and mental health of informal caregivers;<sup>iii</sup>
- Greater focus on data transparency and data sharing, including for ‘failed’ studies;
- Increased harmonization and, where possible, integration with other countries’ national research programs and with private sector research enterprises including industry, academe, and philanthropic funders;<sup>iv</sup>
- Prioritization for reimagining the status quo clinical trial recruitment and retention system that is unacceptably slow, uncertain, expensive, and burdensome on participants and their informal caregivers, and lacking in participant diversity, all of which intolerably delays new means of prevention, detection, diagnosis, care, treatment, and cure.

Thank you for considering our views and for your commitment to overcoming all causes of dementia. Please contact Ian Kremer, executive director of Leaders Engaged on Alzheimer's Disease (the LEAD Coalition),<sup>v</sup> at [ikremer@leadcoalition.org](mailto:ikremer@leadcoalition.org) or (571) 383-9916, with questions or for additional information. We look forward to continuing to work collaboratively with NIH and our partners throughout the research community.

Sincerely,

Abe's Garden

ACT on Alzheimer's

ActivistsAgainstAlzheimer's

African American Network  
Against Alzheimer's

Ageless Alliance

Allergan

Alliance for Aging Research

Alliance for Home Health Quality &  
Innovation

Alliance for Patient Access

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 Association for Geriatric  
Psychiatry

American Association for Long Term Care  
Nursing

American Federation for Aging Research  
(AFAR)

Assisted Living Federation of America

Banner Alzheimer's Institute

Beating Alzheimer's by Embracing Science

Blanchette Rockefeller Neurosciences  
Institute

Soo Borson MD (University of Washington  
Schools of Medicine and Nursing\*)

James Brewer, M.D., Ph.D. (UC San Diego  
and Alzheimer's Disease Cooperative  
Study\*)

BrightFocus Alzheimer's Disease Research

Christopher M. Callahan, MD  
(Indiana University Center for  
Aging Research\*)

Caregiver Action Network

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  
BrainHealth at The University of Texas at  
Dallas\*)

ClergyAgainstAlzheimer's

Cleveland Clinic Foundation

Cognition Therapeutics

CorTechs Labs

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

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

Dementia Alliance International

Department of Neurology, Washington University School of Medicine

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

Farida Kassim Ejaz, Ph.D., LISW-S (Benjamin Rose Institute on Aging\*)

Gary Epstein-Lubow, MD (Alpert Medical School of Brown University\*)

Fujirebio

Sam Gandy, MD, PhD (Icahn School of Medicine at Mount Sinai\*)

Joseph E. Gaugler, Ph.D. (School of Nursing, Center on Aging, University of Minnesota\*)

General Electric Healthcare

Georgia Institute on Aging

Georgetown University Medical Center Memory Disorders Program

Gerontological Society of America

Laura N. Gitlin, PhD (Johns Hopkins School of Medicine\*)

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 Foundation of America

Indiana University Center for Aging Research

Johns Hopkins School of Nursing Center for Innovative Care in Aging

Katherine S. Judge PhD (Cleveland State University\*)

Keep Memory Alive

LatinosAgainstAlzheimer's

Latino Alzheimer's and Memory Disorders Alliance

LeadingAge

Linked Senior, Inc

LuMind Research Down Syndrome Foundation

Merck

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

David G. Morgan, PhD (USF Health Byrd Alzheimer's Institute\*)

Mount Sinai Center for Cognitive Health

National Alliance for Caregiving

National Association of Activity Professionals

National Certification Council for Activity Professionals

National Council for Behavioral Health

National Down Syndrome Society

National Hispanic Council On Aging (NHCOA)

National Task Group on  
Intellectual Disabilities and  
Dementia Practices

Neurocern

New York Academy of Sciences

NFL Neurological Center

OWL-The Voice of Women 40+

Pat Summitt Foundation

Piramal Imaging S.A.

Planetree

Presence Care Project

Prevent Alzheimer's Disease 2020

ResearchersAgainstAlzheimer's

Stephen Salloway, M.D., M.S. (The Warren  
Alpert Medical School of Brown  
University\*)

Second Wind Dreams, Inc./  
Virtual Dementia Tour

Reisa A. Sperling, MD, MMSc (Center for  
Alzheimer Research and Treatment,  
Harvard Medical School\*)

Rudolph Tanzi, PhD (Department of  
Neurology, MGH/Harvard Medical  
School\*)

The Evangelical Lutheran Good Samaritan  
Society

Geoffrey Tremont, Ph.D., ABPP-CN (Alpert  
Medical School of Brown University\*)

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

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://appropriations.house.gov/uploadedfiles/hrpt-114-hr-fy2016-laborhhsed.pdf> *"The Committee has provided a \$300,000,000 increase for Alzheimer's disease research initiative in the National Institute on Aging..."*

<sup>ii</sup> <https://www.congress.gov/114/crpt/srpt74/CRPT-114srpt74.pdf> *"NIH-funded research is the only way to manage this disease in the future. Therefore, the Committee recommendation includes an increase of approximately \$350,000,000 for the National Institute on Aging, the NIH Institute with the primary responsibility for preventing, treating, and curing Alzheimer's disease."*

<sup>iii</sup> [http://www.leadcoalition.org/?wpfb\\_dl=158](http://www.leadcoalition.org/?wpfb_dl=158)

<sup>iv</sup> <http://appropriations.house.gov/uploadedfiles/hrpt-114-hr-fy2016-laborhhsed.pdf> *"The Committee requests NIA to convene a working group of stakeholders, including patient advocacy organizations and nonprofit funders of Alzheimer's and dementia research, within 180 days of enactment of this act to develop possible frameworks and strategies for a direct public-private partnership to fund meritorious research proposals on Alzheimer's Disease that are not supported directly by NIH. NIH shall provide a report annually in its fiscal year 2017 and out year budget requests identifying the total level of NIH peer-reviewed research supported by qualified third party Alzheimer's Disease researchers through such a partnership."*

<sup>v</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 all causes of dementia -- including Alzheimer's disease, vascular disease, Lewy body disease and frontotemporal degeneration -- 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.