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\(^{*}\) to 60\(^{*}\)\(^{*}\) 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;\(^{**}\)

• 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;\(^{iv}\)

• 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), at 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
Activists Against Alzheimer'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*)
Clergy Against Alzheimer'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 Summit 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.
The Committee has provided a $300,000,000 increase for Alzheimer’s disease research initiative in the National Institute on Aging…

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.

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.

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.