LEAD
Leaders Engaged on Alzheimer's Disease

September 14, 2021

Dear Senator :

We sincerely thank you and your colleagues for recognizing and decisively responding to the challenges of Alzheimer's disease and other forms of dementia (including vascular, Lewy body dementia, frontotemporal degeneration, and Creutzfeldt-Jakob disease). Congressional determination to make dementia a national priority has been evident, powerful, and effective. From passage of the National Alzheimer's Project Act, to historic funding increases for Alzheimer's research, and legislation that improves quality of life for those facing dementia while strengthening the scientific enterprise, Congress has recognized overcoming dementia as a budgetary necessity, an economic priority, and a health and moral imperative. In furtherance of this Congressional established national priority, **we encourage you to become a co-sponsor of the bicameral, bipartisan *Concentrating on High-Value Alzheimer's Needs to Get to an End (CHANGE) Act* (S. 1692).**

The CHANGE Act will strengthen dementia detection and diagnosis, in turn catalyzing improved care, helping promote health equity, and accelerating science to prevent, effectively treat and eventually cure Alzheimer's disease and related forms of dementia. Specifically, the CHANGE Act:

- Directs the Centers of Medicare and Medicaid Services (CMS) to require use of cognitive impairment detection tools identified by the National Institute on Aging during Medicare Annual Wellness Visits (AWV) and Welcome to Medicare Visits (WMV). Use of these tools will allow clinicians to better detect mild cognitive impairment and other early symptoms of Alzheimer's disease and related forms of dementia. If cognitive impairment is detected, patients are to be referred for additional testing, to community-based support services, and to appropriate clinical trials.

- Requires CMS to lead, create, adopt, and recognize quality measures and incentives to promote the detection and diagnosis of Alzheimer's disease or related forms of dementia, disclosure of diagnosis, and appropriate care planning services, including potential for clinical trial participation.

CMS encourages, but does not require, providers to use a brief validated structured cognitive assessment tool. However, under current law, Medicare reimbursement is available to providers who use only "direct observation" to assess patients' cognitive health. We know of no authoritative source or evidence-based rationale supporting use of direct observation as a means of adequately detecting early cognitive impairment. In fact, direct observation is the least useful and least appropriate tool, all too often contributing to under-diagnosis, delayed diagnosis, misdiagnosis, and non-disclosure of diagnosis. Such failure carries extraordinary potential to harm any patient and to deepen existing health disparities for women, people of color, rural populations, economically disadvantaged people, and adults with pre-existing cognitive conditions (such as autism, Down syndrome, intellectual disability, severe psychiatric diagnoses, etc.). Recent studies showed that among patients aged 70 years or older, seen in primary care settings, cognitive impairment goes unrecognized in more than 50% of cases. Among older Latinx adults, approximately 40% have undiagnosed cognitive symptoms for 3 years or more. Underutilization of validated assessment tools delays cognitive impairment detection and diagnosis, resulting in decreased opportunities for people to access timely treatment options, including clinical research participation.

Providers need not rely on direct observation alone. Free, easy-to-use, validated assessment tools exist and a number of these tools are listed on the National Institute on Aging (NIA) website. The CHANGE Act requires Medicare both to equip providers to use these tools and to be incentivized for their uniform use, which will improve care for millions of American families currently facing dementia. When people receive a timely and accurate diagnosis, they have improved opportunities to make informed and productive medical, financial, legal, and spiritual choices to strengthen both their own quality of life and that of their family caregivers.

Additionally, as research increasingly focuses on intervening at the earliest point in the disease trajectory, shortcomings in disease detection impede progress toward breakthrough therapies. The CHANGE Act strengthens providers' readiness to conduct timely and accurate cognitive assessment, convey a diagnosis, and deliver comprehensive care planning services including referral to clinical trials.

The CHANGE Act comes at a time of deepening urgency and expanding opportunity. While the need never has been greater, Congress and federal agencies are taking unprecedented action to build comprehensive, integrated and transformative solutions.

Please join in cosponsoring this important legislation to advance diagnosis, treatment, research progress, and support for individuals living with dementia and for family caregivers. **If you have questions or would like to cosponsor this bill, please contact Dana Richter (dana_richter@capito.senate.gov) with Senator Capito or Alex Graf (Alex_graf@stabenow.senate.gov) with Senator Stabenow.**

Thank you for considering our views and for your commitment to overcoming Alzheimer's disease and other forms of dementia. For any questions or additional information about this or other policy issues, please contact Ian Kremer, executive director of Leaders Engaged on Alzheimer's Disease (the LEAD Coalition),[i] ikremer@leadcoalition.org or (571) 383-9916.

Sincerely,

Acadia Pharmaceuticals Inc

ACCSES – The Voice of Disability Service Providers

ActivistsAgainstAlzheimer's Network

ADvancing States

African American Network Against Alzheimer's

AgeneBio

Neelum T. Aggarwal, MD (Rush University Medical Center*)

Aging Life Care Association®

Paul S. Aisen, MD (Keck School of Medicine of USC, Alzheimer's Therapeutic Research Institute*)

Benedict C. Albensi, PhD, BCMAS, CRQM (Nova Southeastern University*)

Alliance for Aging Research

Alliance for Patient Access

Alzheimer's & Dementia Alliance of Wisconsin

Alzheimer’s Drug Discovery Foundation

Alzheimer’s Foundation of America

Alzheimer's Los Angeles

Alzheimer's New Jersey

Alzheimer's Orange County

Alzheimer's San Diego

Alzheimer's Tennessee

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

American Association for Geriatric Psychiatry

American Academy of Neurology

American Brain Coalition

American Federation for Aging Research (AFAR)

American Geriatrics Society

American Medical Women's Association

American Society of Consultant Pharmacists (ASCP)

American Society on Aging

Edward F. Ansello, Ph.D.(Virginia Commonwealth University*)

Brian S. Appleby, M.D. (Case Western Reserve University School of Medicine*)

Association of California Caregiver Resource Centers (ACCRC)

Athira Pharma

Rhoda Au, PhD (Boston University School of Medicine*)

Autistic Women & Nonbinary Network — AWN

Avanir

Laura D. Baker, PhD (Wake Forest University Health Sciences*)

The Balm In Gilead, Inc.

David M. Bass, PhD (Benjamin Rose Institute on Aging*)

Baylor Scott & White Health

Andrew R. Bender, Ph.D. (Michigan State University*)

Benjamin Rose Institute on Aging

Biogen

B'nai B'rith International

Marie Boltz, PhD, GNP-BC, FGSA, FAAN (Penn State College of Nursing*)

Alice Bonner, PhD, RN, FAAN (Johns Hopkins University School of Nursing*)

Soo Borson MD (USC Keck School of Medicine*)

Andrea Bozoki, MD, FAAN (University of North Carolina, Chapel Hill*)

The Brain Donor Project

Bridge Builder Strategies

BrightFocus Foundation

Caregiver Action Network

Caregiver Voices United

Caregivers on the Homefront

CaringKind, The Heart of Alzheimer's Caregiving

Jennifer Carson, Ph.D. (University of Nevada, Reno*)

Center for BrainHealth at The University of Texas at Dallas

Center to Advance Palliative Care

Center for Alzheimer Research and Treatment, Harvard Medical School

Chambers-Grundy Center for Transformative Neuroscience, Department of Brain Health, UNLV

Marianne Chanti-Ketterl, PhD, MSPH (Bryan Alzheimer’s Disease Research Program, Duke University*)

Sandra Bond Chapman, PhD (Center for BrainHealth at The University of Texas at Dallas*)

Joshua Chodosh, MD, MSHS, FACP (New York University*)

ClergyAgainstAlzheimer's Network

Cleveland Clinic Lou Ruvo Center for Brain Health, Nevada

CNS Innovations

Coalition of Wisconsin Aging and Health Groups

The Coelho Center for Disability Law, Policy and Innovation

Cognitive Dynamics Foundation

Tara A. Cortes PhD, RN, FAAN (NYU Rory Meyers College of Nursing, The Hartford Institute for Geriatric Nursing*)

Council on Radionuclides and Radiopharmaceuticals, Inc. (CORAR)

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

Creutzfeldt-Jakob Disease Foundation

Jeffrey Cummings, MD, ScD (University of Nevada Las Vegas*)

CurePSP

Darmiyan

Walter Dawson, Dphil (Oregon Health & Science University*)

Dementia Alliance International

Dementia Alliance of North Carolina

Dementia Palliative Education Network

Department of Neurology, Washington University School of Medicine

N. Maritza Dowling PhD (The George Washington University School of Nursing*)

Drexel University College of Nursing and Health Professions

Eisai Co., Ltd.

Eli Lilly and Company

The Emory Goizueta Alzheimer’s Disease Research Center

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

Anne Fabiny, MD (San Francisco VAHCS and UCSF*)

Faith United Against Alzheimer's Coalition

Family Caregiver Alliance

Brent P. Forester, MD, MSc (Harvard Medical School*)

Fujirebio

Seth A. Gale, M.D. (Brigham and Women’s Hospital, Harvard Medical School*)

Michela Gallagher, PhD (Johns Hopkins University School of Medicine*)

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

Joseph E. Gaugler, PhD (School of Public Health, University of Minnesota*)

Genentech

Genetic Alliance

Daniel R. George, Ph.D, M.Sc (Penn State College of Medicine*)

Georgetown University Medical Center Memory Disorders Program

Gerontological Advanced Practice Nurses Association

The Gerontological Society of America

Laura Gillen, MS (McDaniel College*)

Laura N. Gitlin, PhD (Drexel University, College of Nursing and Health Professions*)

Global Alzheimer's Platform Foundation

Global CEO Initiative on Alzheimer's Disease

Global Coalition on Aging

Danielle Goldfarb, MD (University of Arizona College of Medicine*)

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

The Hartford Institute for Geriatric Nursing, NYU Rory Meyers College of Nursing

Mark D. Hayward, Ph.D. (The University of Texas at Austin*)

Healthcare Leadership Council

HealthMatters Program

HealthyWomen

Megan Thomas Hebdon, PhD, DNP, RN, NP-c (University of Texas at Austin School of Nursing*)

J. Neil Henderson, PhD (University of Minnesota Medical School*)

Patricia C. Heyn, PhD, FGSA, FACRM (University of Colorado Denver Anschutz Medical Campus*)

HFC (formerly Hilarity for Charity)

Nikki L. Hill, PhD, RN (The Pennsylvania State University, Ross and Carol Nese College of Nursing*)

Nancy A. Hodgson, RN, PhD, FAAN (University of Pennsylvania School of Nursing*)

David P Hoffman DPS CCE (Maria College*)

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

Home Instead Senior Care

William Hu MD, PhD, FAAN (Rutgers University*)

Huffington Center on Aging, Baylor College of Medicine

Hypertrophic Cardiomyopathy Association

ICAN, International Cancer Advocacy Network

International Association for Indigenous Aging

Iona Senior Services

IQVIA

Shannon Jarrott, Ph.D. (Ohio State University*)

Kathy Jedrziewski, PhD (University of Pennsylvania*)

Lee A. Jennings, MD, MSHS (University of Oklahoma Health Sciences Center*)

Johns Hopkins Memory and Alzheimer's Treatment Center

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

Justice In Aging

Nicholas Kanaan, PhD (Michigan State University*)

Jason Karlawish, MD (Penn Memory Center, University of Pennsylvania*)

Keck School of Medicine of USC, Alzheimer's Therapeutic Research Institute

K-T Support Group (Klippel-Trenaunay Support)

Latino Alzheimer’s and Memory Disorders Alliance

LatinosAgainstAlzheimer’s

LeadingAge

Allan Levey, MD, PhD (Emory University School of Medicine*)

Lewy Body Dementia Association

Life Molecular Imaging

Linked Senior, Inc

Livpact Inc.

Lundbeck Pharmaceuticals LLC

Lupus and Allied Diseases Association, Inc

Kostas Lyketsos, M.D., M.H.S. (Johns Hopkins Memory and Alzheimer's Treatment Center*)

Yannick Marchalant, Ph.D. (Central Michigan University*)

Beth Marks, PhD, RN, FAAN (University of Illinois at Chicago*)

David X. Marquez, PhD (Department of Kinesiology and Nutrition, University of Illinois at Chicago*)

Medical Imaging & Technology Alliance (MITA)

Merck

Michigan State University Alzheimer's Alliance

Milken Institute Center for the Future of Aging

Minnesota Association of Area Agencies on Aging

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

MLD Foundation

David G. Morgan, PhD (Michigan State University*)

Darby Morhardt, PhD, LCSW (Northwestern University Feinberg School of Medicine*)

Laura Mosqueda MD (Keck School of Medicine of USC*)

Mount Sinai Center for Cognitive Health

National Alliance for Caregiving

National Asian Pacific Center on Aging

National Association of Activity Professionals

National Association of Counties (NACo)

National Association of Social Workers (NASW)

National Association of State Long-Term Care Ombudsman Programs (NASOP)

National Certification Council for Activity Professionals

National Consumers League

National Consumer Voice for Quality Long-Term Care

National Hispanic Council On Aging (NHCOA)

National Indian Council on Aging (NICOA)

National Prion Disease Pathology Surveillance Center

National Task Group on Intellectual Disabilities and Dementia Practices

NFL Neurological Center

Noah Homes

NYU Langone Alzheimer’s Disease Center

NYU Langone Center on Cognitive Neurology

NYU Langone Health

The Ohio Council for Cognitive Health

Organic Acidemia Association

Otsuka America Pharmaceutical Inc.

Van Ta Park, PhD, MPH (University of California, San Francisco*)

Monica W. Parker, MD (Goizueta Alzheimer’s Disease Research Center, Emory University*)

Patients Rising

Pat Summitt Foundation

Penn Program on Precision Medicine for the Brain (P3MB)

Tressa Nese and Helen Diskevich Center of Geriatric Nursing Excellence at Penn State

Planetree International, Inc.

Anton P. Porsteinsson, M.D. (University of Rochester School of Medicine and Dentistry*)

Daniel C. Potts, MD, FAAN (University of Alabama College of Community Health Sciences*)

Melinda C. Power, ScD (Milken Institute School of Public Health, George Washington University*)

Prevent Alzheimer's Disease 2020

PXE International

Peter Reed, PhD (Sanford Center for Aging, University of Nevada Reno*)

ResearchersAgainstAlzheimer’s

David B. Reuben, MD (David Geffen School of Medicine at UCLA*)

Theresa Rohr-Kirchgraber, MD, FACP, FAMWA (Augusta University/University of Georgia Medical Partnership*)

Marwan Sabbagh, MD, FAAN (Cleveland Clinic Lou Ruvo Center for Brain Health*)

Tatiana Sadak, PhD, PMHNP, ARNP (University of Washington School of Nursing*)

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

Quincy Miles Samus, PhD, MS (Johns Hopkins School of Medicine*)

Second Wind Dreams, Inc./ Virtual Dementia Tour

Amanda G. Smith, M.D. (USF Health Byrd Alzheimer's Institute*)

Society for Women's Health Research

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

Alan B. Stevens, PhD (Baylor Scott & White Health, Center for Healthcare Policy*)

Sudden Arrhythmia Death Syndromes (SADS) Foundation

Russell H. Swerdlow, M.D. (University of Kansas School of Medicine*)

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

Pierre N. Tariot, MD (University of Arizona College of Medicine*)

Texas Rare Alliance

The Association for Frontotemporal Degeneration

The Memory Impairment and Neurodegenerative Dementia (MIND) Center, University of Mississippi Medical Center

The Youth Movement Against Alzheimer’s

Trellis/ACT on Alzheimer’s

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

R. Scott Turner, MD, PhD (Georgetown University Memory Disorders Program*)

UCLA Mary S. Easton Center for Alzheimer's Disease Research, David Geffen School of Medicine

University of Minnesota Center for Healthy Aging and Innovation (CHAI)

University of Rochester Alzheimer's Disease Care, Research and Education Program (AD-CARE)

UsAgainstAlzheimer’s, LEAD Coalition co-convener

USAging

USF Health Byrd Alzheimer's Institute

VeteransAgainstAlzheimer’s

Virginia Center on Aging

Anand Viswanathan, MD, PhD (Massachusetts General Hospital and Alzheimer’s Disease Research Center*)

Stella L. Volpe, PhD, RDN, ACSM-CEP, FACSM (Virginia Tech*)

Volunteers of America, LEAD Coalition co-convener

Keith Vossel, MD, MSc (Mary S. Easton Center for Alzheimer's Disease Research, David Geffen School of Medicine at UCLA*)

Victoria Walker, MD CMD (Sanford School of Medicine, University of South Dakota*)

David A. Weidman, MD, FAAN (Banner Alzheimer's Institute*)

Carol J. Whitlatch, PhD (Benjamin Rose Institute on Aging*)

Nancy Wilson, MA LCSW (Baylor College of Medicine*)

WomenAgainstAlzheimer’s

Women's Brain Project

Julie M. Zissimopoulos, Ph.D. (University of Southern California*)

** Affiliations of individual researchers are for identification purposes only and do not necessarily represent the endorsement of affiliated institutions.*

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[i] 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, large health systems, and biotechnology and pharmaceutical companies. The LEAD Coalition works collaboratively to focus the nation’s strategic attention on dementia in all its causes -- including Alzheimer’s disease, vascular disease, Lewy body dementia, frontotemporal degeneration and Creutzfeldt-Jakob disease -- 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.