Brain Health Equity Legislative Agenda

There has never been a more urgent time to address the impact of Alzheimer’s on women and communities of color. Black Americans are approximately two times more likely, and Latinos are 1.5 times more likely to develop Alzheimer’s and related dementias than non-Latino Whites. Women make up two-thirds of all Alzheimer’s patients, and more than 60 percent of unpaid Alzheimer’s caregivers are women.

If nothing is done, by 2030 nearly 40 percent of all Americans living with Alzheimer’s will be Latino or Black.

Congress can take action to promote health equity in our national response to Alzheimer’s by supporting the policies outlined in this agenda.

DRIVE EQUITY IN AN EARLY AND ACCURATE DIAGNOSIS

- Concentrating on High-Value Alzheimer’s Needs to Get to an End (CHANGE) Act of 2021 (H.R. 3354/S. 1692) - Despite a higher risk for Alzheimer’s disease and related dementias, Black Americans and Latinos are much less likely to receive an accurate and timely diagnosis compared to their non-Hispanic White counterparts. The CHANGE Act would improve early detection by directing the Centers for Medicare and Medicaid Services (CMS) to require use of cognitive impairment detection tools identified by the National Institute on Aging during the Annual Wellness Visit and Welcome to Medicare visit. Use of these tools will allow clinicians to better detect mild cognitive impairment and other early symptoms of Alzheimer’s and related dementias.

DRIVE EQUITY IN CARE

- Establish a paid family and medical leave policy that covers family caregivers of older adults - Research is clear that both caregivers and their loved ones benefit physically, emotionally, and financially from having access to paid family and medical leave, yet the United States is the only industrialized nation not to offer it. Paid family and medical leave can help provide individuals and families the economic security they need as they navigate complex diagnoses, treatments, and care journeys.

- Comprehensive Care for Alzheimer’s Act (H.R. 2517/S. 1125) - The bipartisan Comprehensive Care for Alzheimer’s Act would ask the Center for Medicare and Medicaid Innovation (CMMI) to test a different payment structure where providers are reimbursed through an annual per-patient payment so that providers can afford the upfront costs associated with developing and implementing a dementia care management program.

- Credit for Caring Act (H.R. 3321) - The bipartisan Credit for Caring Act would create up to a $5,000 nonrefundable tax credit for family caregivers, which can be applied to incurred caregiving expenses greater than $2,000. Caregiving expenses can include transportation, home modifications for accommodations, medication management, and training and education for the caregiver.

DRIVE EQUITY IN CLINICAL RESEARCH

- The Equity in Neuroscience and Alzheimer’s Clinical Trials (ENACT) Act of 2021 (H.R. 3085/S. 1548) - The ENACT Act would improve clinical trial participant diversity, which is important in treatment development, by increasing the number of Alzheimer’s clinical trials in areas with high concentrations of underrepresented populations, requiring grantees to do outreach to underrepresented populations, and provide funding to the National Institute on Aging to expand education and outreach and increase clinical trial staff diversity.

ADEQUATELY INVEST IN ALZHEIMER’S PREVENTION, RESEARCH, TREATMENT, AND PUBLIC HEALTH EFFORTS. FOR FY 2022, WE ENCOURAGE THE FOLLOWING LABOR-HHS APPROPRIATIONS REQUESTS:

- Support $60 million for the CDC’s Alzheimer’s Disease and Healthy Aging Program (ADHAP) - The ADHAP is CDC’s only program dedicated specifically to promoting the health of older Americans across multiple chronic conditions and health equity. Yet, for FY21, only $20.5 million was allocated for ADHAP, which represented just 0.25% of the overall CDC budget.

- Support an increase of $289 million from FY21 levels for Alzheimer’s disease and related dementias (ADRD) research at the National Institute on Aging (NIA)- Sustained investments in NIH-funded Alzheimer’s research can accelerate progress and discoveries as articulated in the Bypass Budget Proposal for Fiscal Year 2022 and fund health disparities research to deepen our understanding of Alzheimer’s in communities of color and women.

- Support $2.2 billion for Federally Qualified Health Centers (FQHCs) - FQHCs help address cultural, linguistic, and other barriers to care by delivering coordinated and comprehensive primary and preventive services – helping to reduce health disparities in medically-underserved communities across the nation.