



The Honorable Anna Eshoo
U.S. House of Representatives
272 Cannon House Office Building
Washington, D.C. 20515

The Honorable Brian Fitzpatrick
U.S. House of Representatives
271 Cannon House Office Building
Washington, D.C. 20515

The Honorable Robin Kelly
U.S. House of Representatives
2416 Rayburn House Office Building
Washington, D.C. 20515

April 12, 2022

Dear Representatives Eshoo, Fitzpatrick, and Kelly:

On behalf of the Alzheimer's Association and the Alzheimer's Impact Movement (AIM), including our nationwide network of advocates, thank you for your continued leadership on issues and legislation important to Americans living with Alzheimer's and other dementia, and to their caregivers. The Alzheimer's Association and AIM write today to support the H.R. 6584, Diverse and Equitable Participation in Clinical Trials (DEPICT) Act, which would enhance data reporting requirements on clinical trial demographics and provide funding to various entities to improve access to clinical trials.

The burden of Alzheimer's on individuals and families continues to grow. Today, more than 6 million Americans aged 65 and older are living with Alzheimer's dementia and by mid-century, this number is expected to nearly double. Total payments for all individuals living with this disease are estimated at \$321 billion (not including unpaid caregiving). Medicare and Medicaid are expected to cover \$206 billion, or 64 percent of the total health care and long-term care payments for people with Alzheimer's or other dementias. Total payments for health care costs, including hospice care, for people with Alzheimer's and other dementias are projected to increase to nearly \$1 trillion by 2050. These mounting costs threaten to bankrupt families, businesses, and our health care system. Unfortunately, our work is only growing more urgent.

Alzheimer's and other dementia disproportionately affect older Black and Hispanic Americans compared to older White Americans. Black Americans are about twice as likely to develop Alzheimer's and Hispanic Americans are about one and a half times more likely to develop the disease. However, much of the Alzheimer's research to date has not included sufficient numbers of Black, Hispanic, Asian and Native Americans to be representative of the U.S. population. The underrepresentation of these populations not only hinders the ability of researchers to understand these health disparities, it also restricts their knowledge of how an approved therapy or diagnostic may affect the population most likely to need the treatment. There is therefore an urgent need for current and future research to include increased numbers of Black, Hispanic, Asian and Native Americans in clinical trials to ensure everyone benefits from advances in Alzheimer's science.

According to the *Alzheimer's Association 2021 Alzheimer's Disease Facts and Figures special report*, nearly two-thirds of Black Americans (62%) believe medical research is biased against people of color — a view shared by substantial numbers of Asian Americans (45%), Native Americans (40%), and Hispanic Americans (36%). In fact, only half of Black Americans (53%) trust a future cure for Alzheimer's will be shared equally regardless of race, color, or ethnicity. This underscores the need to build and restore trust in underrepresented communities.

Efforts to expand diversity for clinical trials, both with Alzheimer's research and generally, are critical toward developing a better understanding of health disparities. The DEPICT Act would require the sponsors of investigational device exemption (IDE) & investigational new drug (IND) applications to include certain demographic data when submitting such an application to the Food and Drug Administration (FDA). Additionally, sponsors must include a Diversity Action Plan that demonstrates how they plan to utilize this data to increase the enrollment of underrepresented populations in clinical trials. The DEPICT Act would provide funding to the National Institutes of Health (NIH) for community engagement and outreach to underrepresented populations regarding clinical trial opportunities and educational resources. Funding would also be provided to qualified entities such as rural health clinics and Federally-Qualified Health Centers to increase capacity for clinical trial participation and research.

The Alzheimer's Association and AIM deeply appreciate your continued leadership on behalf of all Americans living with Alzheimer's and other dementia. If you have any questions about this or any other legislation, please contact Rachel Conant, Vice President of Federal Affairs, at rconant@alz-aim.org or at 202.638.7121.

Sincerely,

A handwritten signature in black ink, appearing to read 'REgge', with a long horizontal flourish extending to the right.

Robert Egge
Chief Public Policy Officer, Alzheimer's Association
Executive Director, Alzheimer's Impact Movement