Congress of the United States

Washington, DC 20515

March 24, 2023

The Honorable Robert Aderholt Chairman Subcommittee on Labor, Health and Human Services, and Education Appropriations Washington, DC 20515 The Honorable Rosa DeLauro Ranking Member Subcommittee on Labor, Health and Human Services, and Education Appropriations Washington, DC 20515

Dear Chairman Aderholt and Ranking Member DeLauro:

As strong supporters of Alzheimer's research and health equity, we respectfully write to request \$60 million for initiatives that increase the participation of underrepresented populations in research and clinical trials under the National Institutes of Health (NIH) in the Fiscal Year 2024 Labor, Health and Human Services, Education, and Related Agencies Appropriations bill.

As of 2022, more than 6.5 million Americans were living with Alzheimer's disease, representing 10.7% of the population over the age of 65. Although Alzheimer's and other dementia disproportionately affect non-white communities, these communities continue to be underrepresented in Alzheimer's disease clinical trials. Black Americans are about twice as likely to develop the disease, yet represent only 5% of all clinical trial participants. Hispanic Americans are nearly one and a half times more likely to develop Alzheimer's, but only represent around 1% of clinical trial participants. Available data suggests that participation of Native Americans and Asian Americans in clinical trials is also very low, leading to an inadequate representation of the total population living with Alzheimer's across the country.

The underrepresentation of these populations not only hinders the ability of researchers to understand the extent of these health disparities, but also restricts their knowledge of how an approved therapy or diagnostic may affect the population most in need of the treatment. According to the CDC, the number of Americans projected to be diagnosed with Alzheimer's will nearly triple to 14 million by the year 2060. Therefore, there is an urgent need for current and future research to include a higher proportion of non-white Americans to ensure that every American can benefit from scientific advances in this field.

We are grateful to you both that the Consolidated Appropriations Act, 2023 (P.L. 117-328) included language to help increase the participation of underrepresented populations in Alzheimer's and other dementia clinical trials. While this was a great first step, there is limited funding available to expand access to clinical trials and research for non-white Alzheimer's patients. Increased funding for these initiatives will allow the NIH to work directly with stakeholders to promote participation in clinical trials within underrepresented populations and reduce the burden of participating. These efforts will include expanding community engagement and outreach to these populations, incentivizing trial locations in areas of unmet need, and utilizing technology like remote patient monitoring, to improve clinical trial participation and retention.

We appreciate your consideration of our request to provide \$60 million to help increase the participation of underrepresented populations in Alzheimer's and other dementia clinical trials in FY 2024.

Sincerely,

Lisa Blunt Rochester Member of Congress

Jacob Member of Congress

Madeleine Dean

Madeleine Dean Member of Congress

Eleanor Holmes Norton Member of Congress

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Jan Schakowsky Member of Congress

<u>Manette</u> Diaz Barragar Nanette Diaz Barragán

Nanette Díaz Baffagán Member of Congress

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Robin L. Kelly Member of Congress

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Ritchie Torres Member of Congress

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Anna G. Eshoo Member of Congress

Ann McLane Kuster Member of Congress

André Carson

André Carson Member of Congress

Seah Casten Member of Congress

Nikema Williams Member of Congress

Alma S. Adams, Ph.D. Member of Congress

Val Hoyle Member of Congress

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Steve Cohen Member of Congress

Brian Higgins Member of Congress

Emanuel Cleaver, II Member of Congress

Seth ziner Member of Congress

Marc A. Veasey

Marc A. Veasey Member of Congress