



The Honorable Lisa Blunt Rochester
U.S. House of Representatives
1724 Longworth House Office Building
Washington, DC 20515

The Honorable Jaime Herrera Beutler
U.S. House of Representatives
2352 Rayburn House Office Building
Washington, DC 20515

The Honorable Chris Smith
2373 Rayburn House Office Building
U.S. House of Representatives
Washington, DC 20515

The Honorable John Curtis
2400 Rayburn House Office Building
U.S. House of Representatives
Washington, DC 20515

The Honorable Maxine Waters
2221 Rayburn House Office Building
U.S. House of Representatives
Washington, DC 20515

September 24, 2021

Dear Representatives Blunt Rochester, Herrera Beutler, Smith, Curtis and Waters:

On behalf of the undersigned organizations, thank you for your continued leadership on issues and legislation important to Americans living with Alzheimer's and other dementias and to their caregivers. We are proud to strongly support the bipartisan Equity in Neuroscience and Alzheimer's Clinical Trials (ENACT) Act (H.R. 3085/S. 1547), which would increase the participation of underrepresented populations in Alzheimer's and other dementia clinical trials by expanding education and outreach to these populations, encouraging the diversity of clinical trial staff, and reducing participation burden, among other priorities.

Alzheimer's and other dementia disproportionately affect underrepresented communities, including older Black and Hispanic Americans. Black Americans are twice as likely to develop Alzheimer's and Hispanic Americans are 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 Blacks, Hispanics, Asian Americans/Pacific Islanders and Native Americans to be representative of the U.S. population. In fact, Blacks represented only five percent of all clinical trial participants and Hispanics represented only one percent, despite representing 13 percent and 18 percent of the population, respectively. Available data suggest that participation of Native Americans in clinical trials is also very low.

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 Blacks, Hispanics, Asian Americans/Pacific Islanders, 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 on Race, Ethnicity and Alzheimer's in America*](#), 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%) as well. 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. Strong community relationships can serve to address misconceptions and mistrust about research because the community has a sense of ownership in the research initiative. Community-based participatory research and engagement with community-based organizations are two strategies that can accomplish this goal.

The bipartisan ENACT Act would help increase the diversity of Alzheimer's and other dementia clinical trials in several important ways. First, the bill would provide funding for the National Institute on Aging (NIA) to expand the number of Alzheimer's Disease Research Centers (ADRCs) in areas with higher concentrations of underrepresented populations, such as through entities like Historically Black Colleges and Universities, Hispanic-Serving Institutions, Tribal Colleges and Universities, or centers of excellence for other underrepresented populations. The ENACT Act would provide funding for ADRCs and Resource Centers for Minority Aging Research (RCMARs) to increase education and outreach to underrepresented communities and primary care physicians to let them know about current trial opportunities, the importance of participation, and the disparate impact of the disease on their populations. Importantly, ADRCs and RCMARs would use community-based participatory research strategies in their outreach to underrepresented populations.

The ENACT Act would also direct NIA to enhance the diversity of principal investigators and study staff conducting Alzheimer's and other dementia clinical trials, so they are more representative of the populations they're trying to enroll. The bill directs NIA to provide training to principal investigators from underrepresented populations on topics like clinical protocols and how to apply for grants, so they have the necessary expertise. NIA would also ensure senior researchers from underrepresented populations are included when making awards for leadership and excellence in Alzheimer's research.

Finally, the ENACT Act would reduce participation burden to make it easier for underrepresented populations to participate in Alzheimer's and other dementia clinical trials by providing incentives for locating Alzheimer's clinical trial sites in areas with high concentrations of underrepresented populations, as identified by data from the U.S. Census and Medicare claims. The bill would direct NIA to ensure grantees use community-based participatory research strategies in their outreach to underrepresented populations. The bill also encourages the use of remote health technology in communities, such as remote patient monitoring, to ease

the burden of participation. Importantly, the bill would direct NIA to ensure grantees appropriately budget for outreach activities to underrepresented populations and include a description of outreach plans. NIA would also encourage grantees to engage with community-based organizations in efforts to increase clinical trial participation of underrepresented populations.

Again, we deeply appreciate your extraordinary and continued leadership on issues important to the millions of people living with Alzheimer's and their caregivers. We look forward to working with you to ensure this bipartisan bill is enacted into law to bring more equitable representation to Alzheimer's and other dementia clinical trials.

Sincerely,

Alzheimer's Association
Alzheimer's Impact Movement
Alliance for Aging Research
AME International Health Commission
American Academy of Neurology
American Medical Association
Black Nurses Rock
National Asian Pacific Center on Aging
National Black Nurses Association
National Caucus and Center on Black Aging, Inc.
National Hispanic Council on Aging
National Hispanic Medical Association
National Indian Council on Aging
Public Citizen
SAGE (Services & Advocacy for LGBT Elders)
UsAgainstAlzheimer's

[Signatures current as of August 10, 2022]