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

The American Academy of Neurology (AAN), the world’s largest association of neurologists representing 36,000 professionals, is strongly committed to improving the care and outcomes of persons with neurologic illness in a cost-effective manner. One in six people lives with a brain or nervous system condition, including Alzheimer’s disease, Parkinson’s disease, stroke, epilepsy, traumatic brain injury, ALS, multiple sclerosis, and headache. Of these conditions, Alzheimer’s disease and other forms of dementia are particularly widespread, with an estimated 6.2 million Americans living with Alzheimer’s alone.

Older Black and Latinx Americans are much more likely than White Americans to be affected by Alzheimer’s and other dementias, yet many clinical research studies focused on these diseases do not include sufficient data from these populations to be representative of the US population. The underrepresentation of these populations, along with Native American and Asian Americans, hampers our understanding about these health disparities and limits our knowledge of how potential therapeutics may affect populations that need them the most.

Your legislation aims to improve health care equity by taking deliberate actions to foster the inclusion of diversity in clinical trials. The ENACT Act would increase participation of underrepresented populations in dementia clinical trials by expanding education and outreach to these populations, encouraging the diversity of clinical trial staff, and reducing participation burden.
This is critical to addressing the significant well-documented widespread barriers to patient access to care and diverging health care outcomes associated with gender, race, and ethnicity, including in dementia care, as outlined in the Alzheimer’s Association’s Special Report: Race, Ethnicity and Alzheimer’s in America.

We appreciate the work you have done and will continue to do to promote equity and social justice in neurology and the neurosciences. If you have any questions or require additional information, please do not hesitate to contact Derek Brandt, Director of Congressional Affairs at dbrandt@aan.com or Fred Essis, Congressional Affairs Manager at fessis@aan.com. We look forward to working with you as we all strive to improve care for all Americans with neurologic conditions.

Sincerely,

Orly Avitzur, MD
President, American Academy of Neurology