

201 Chicago Avenue Minneapolis, Minnesota 55415

> Tel: (612) 928-6100 Fax: (612) 454-2744

> > AAN.com

#### **President**

Orly Avitzur, MD, MBA, FAAN Tarrytown, New York

## **President Elect**

Carlayne E. Jackson, MD, FAAN San Antonio, Texas

### **Vice President**

Janis M. Miyasaki, MD, MEd, FRCPC, FAAN Edmonton, Alberta, Canada

#### Secretary

Sarah M. Benish, MD, FAAN Minneapolis, Minnesota

### **Treasurer**

Charles C. Flippen II, MD, FAAN Los Angeles, California

## **Immediate Past President**

James C. Stevens, MD, FAAN Fort Wayne, Indiana

# Directors

Wayne E. Anderson, DO, FAHS, FAAN San Francisco, California

Brenda Banwell, MD, FAAN *Philadelphia, Pennsylvania* 

Bruce H. Cohen, MD, FAAN Chair, Advocacy Committee Akron, Ohio

Charlene E. Gamaldo, MD, FAASM, FAAN Baltimore, Maryland

James N. Goldenberg, MD, FAAN Lake Worth, Florida

Larry B. Goldstein, MD, FAHA, FAAN Lexington, Kentucky

Lily Jung Henson, MD, MMM, FAAN Stockbridge, Georgia

Shannon M. Kilgore, MD, FAAN Palo Alto, California

Brett M. Kissela, MD, MS, FAHA, FAAN Cincinnati, Ohio

Brad C. Klein, MD, MBA, FAAN Chair, Medical Economics and Practice Committee Willow Grove, Pennsylvania

José G. Merino, MD, M Phil, FAHA, FAAN Editor-in-Chief, Neurology® Washington, DC

> Bruce Ovbiagele, MD, MSc, MAS, MBA, FAAN San Francisco, California

Maisha T. Robinson, MD, MSHPM, FAAN Chair, Member Engagement Committee Jacksonville, Florida

# Non-voting Board Member Mary E. Post, MBA, CAE

Chief Executive Officer Minneapolis, Minnesota August 3, 2021

The Honorable Lisa Blunt Rochester US House of Representatives Washington, DC 20515

The Honorable Chris Smith US House of Representatives Washington, DC 20515

The Honorable Maxine Waters US House of Representatives Washington, DC 20515

The Honorable Jaime Herrera Beutler US House of Representatives Washington, DC 20515

The Honorable John Curtis US House of Representatives Washington, DC 20515

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.

The AAN is committed to intentional action to be a fully inclusive, deliberately diverse, and anti-racist organization that respects and values our membership, our staff, and the communities we serve. To that end, we work to actively promote equity and social justice in neurology and neurosciences. It is for this reason that the AAN applauds you for introducing H.R. 3085, Equity in Neuroscience and Alzheimer's Clinical Trials (ENACT) Act.

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 affects 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 <u>Alzheimer's Association's Special Report: Race, Ethnicity and Alzheimer's in America</u>.

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 <a href="mailto:dbrandt@aan.com">dbrandt@aan.com</a> or Fred Essis, Congressional Affairs Manager at <a href="mailto:fessis@aan.com">fessis@aan.com</a>. We look forward to working with you as we all strive to improve care for all Americans with neurologic conditions.

Sincerely,

Orly Avitzur, MD, MBA, FAAN

Orly autom MD

President, American Academy of Neurology