

May 4, 2022

The Honorable Lisa Blunt Rochester
U.S. House of Representatives
1724 Longworth House Office Building
Washington, DC 20510

The Honorable Chris Smith
U.S. House of Representatives
2373 Rayburn 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 Maxine Waters
U.S. House of Representatives
2221 Rayburn House Office Building
Washington, DC 20515

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

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

On behalf of our physician and medical student members, the American Medical Association (AMA) is writing in support of H.R. 3085, the “Equity in Neuroscience and Alzheimer’s Clinical Trials Act of 2021,” which would amend the Public Health Service Act to improve the diversity of participants in research on Alzheimer’s disease (AD). The AMA believes that racial and ethnic disparities should be eliminated in health care, and this bill would bring us a step closer to helping make health care more equitable.

To ensure that Alzheimer’s treatments are effective, it is imperative that diverse populations are well represented in clinical studies. However, studies have shown that “[e]thnographically diverse participants continue to be underrepresented in AD clinical trials.”¹ This is a concern because “diverse patient populations generate more valuable and effective treatment data. For example, AD can have different types of medical impacts on different racial groups...”² Another example is that “African Americans are two times more likely to develop Alzheimer’s compared to white” individuals. However, a multitude of Alzheimer studies do not even have a 20 percent African American participation rate.³ Likewise, studies have found that “[c]ommonly used Alzheimer’s clinical trial exclusion criteria have the potential to disproportionately affect African Americans and Hispanics/Latinos.”⁴

The Equity in Neuroscience and Alzheimer’s Clinical Trials Act of 2021 would help implement long needed improvements to diversity in Alzheimer’s research. The funds authorized under this legislation

¹ <https://pubmed.ncbi.nlm.nih.gov/34590409/>.

² <https://acrpn.net.org/2021/10/19/nih-affirms-importance-of-diversity-in-clinical-trial-workforce/>.

³ <https://www.kumc.edu/about/news/news-archive/dementia-research.html>.

⁴ https://aaic.alz.org/releases_2021/clinical-trial-diversity.asp.

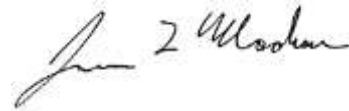
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would be used to establish and operate Alzheimer diagnostic and treatment clinics and clinical trials designed to meet the special needs of minority, rural, and underserved populations. Moreover, this legislation would create cooperative agreements and grants to be used for the planning, establishment, and operation of new centers in areas with a higher concentration of minority groups such as entities that are historically Black colleges and universities, Hispanic-serving institutions, Tribal colleges and universities, or centers of excellence for other minority populations. Additionally, federal payments would be used to establish engagement centers to carry out public outreach, education efforts, and dissemination of information for members of minority groups about clinical trial participation. Furthermore, resource information and technical assistance would be provided to help increase the participation of minority populations in clinical research on AD and to encourage participation of individuals from groups that are underrepresented in the biomedical, clinical, behavioral, and social science fields.

We cannot afford to have continued underrepresentation of diverse patients in clinical trials, which can result in the development of treatments that exacerbate health disparities and inequalities across the United States.⁵ It is important that all communities are included in Alzheimer clinical trials so that all communities can benefit from the scientific advances that will hopefully soon create a cure for this disease. The Equity in Neuroscience and Alzheimer's Clinical Trials Act of 2021 is a positive step towards broadening enrollment practices of Alzheimer clinical trials to reflect clinically relevant populations which in turn will increase the probability a cure will be found.

The AMA commends your ongoing commitment to this important issue, and we look forward to working with you to further advance this legislation.

Sincerely,

A handwritten signature in black ink, appearing to read "James L. Madara". The signature is written in a cursive style with a large initial "J" and "M".

James L. Madara, MD

⁵<https://science.nichd.nih.gov/confluence/display/newsletter/2021/01/27/The+Importance+of+Diversity+in+Clinical+Trials>.