

ADVISORY COUNCIL ON ALZHEIMER'S RESEARCH, CARE, AND SERVICES

Public Comments from Advisory Council Meeting, April 2024

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Comments and questions, or alerts to broken links, should be sent to napa@hhs.gov.

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C. Armstrong | 4-29-2024

Hello. Thank you for the opportunity to speak here today. I am the mother of a young adult with Down syndrome from Thousand Oaks California. I am speaking to you today as an advocate for the Down syndrome community and an ambassador for the National Down Syndrome Society.

Not long after my daughter with Down syndrome was born, my dad began to show cognitive impairment and shortly after receiving a diagnosis of Alzheimer's' disease. His trajectory with the disease was typical and heartbreaking. I watched my father decline as he lost so many of the skills he once had. I also watched my mom go from having a richly meaningful life to suffering the isolation and despair of caring for a husband who was slipping further away each day.

After my mother passed away from pancreatic cancer, I became the sole caregiver for my father when he moved in with me. But after many months, his agitation and impaired mobility were too much for me and our children. Placing him in a memory care facility felt like a broken promise, but keeping my kids safe was more important. Alzheimer's disease had turned a man who had never uttered an angry or unkind word into someone none of us recognized. He passed away six weeks after entering the care facility.

As my knowledge of Down syndrome and the associated medical conditions has grown, I was terrified to learn that the lifetime risk of Alzheimer's disease is over 90% for individuals with Down syndrome. It was agonizing to watch Alzheimer's steal my father's fun-loving personality, to see him become a burden to my mother, to witness his

transformation into a scary figure to my own children whom he adored. Even worse is that now I have to worry about my beautiful daughter. Will this be her fate, too? I fear for so many others like her, many of whom will contract Alzheimer's by their 50's. Yet, it feels like our community has gotten little attention from broader Alzheimer's response efforts.

But this council and each of you have the opportunity to change that. I am here to implore you to change that. Today, I ask you to ensure that individuals with Down syndrome are appropriately included in clinical trials and research, that they have access to new treatments and adequate clinical care and that there are much needed supports for caregivers like me who care tirelessly for our loved ones who are irrevocably changed by this disease.

My daughter does not deserve to suffer like my father suffered. She and other members of our amazing community deserve so much more. Thank you for your time.

S. Garimalla | 4-1-2024

I am writing to submit my comments on the topic of clinical trial participation by minority communities in dementia studies. I am a Gerontology Master's student at Georgia State University. In recent years, we have seen many pharmaceuticals approved for treatment of Alzheimer's dementia disease--notably Donanemab, Lecanemab, and Remternetug. Clinical trials with Donanemab were conducted with a participant group that was 92% white. Similarly, Lecanemab underwent clinical trials with 76% non-Hispanic white participants, 17% Asian participants, 12% Hispanic participants, and only 2.5% Black participants. The lack of significant diversity across clinical trial participants may mean medication may not work the same for everyone, but researchers are only able to assess the range of responses the majority white participant population has. Considering that older Black adults are twice as likely to get diagnosed with Alzheimer's dementia, this discrepancy in clinical trial participation does a great disservice to those vulnerable to dementia symptoms.

I would ask this council to consider the need to increase diversity in recruiting clinical trial participants. One significant aspect of participant recruitment among the Black community would be gaining trust of older adults so they are able to access necessary resources. Advocates work several years to gain the trust of community leaders and key players in order to be able to best serve populations. Sonia Martinez volunteered with the Alzheimer's Association and advocated for nine years for the Hispanic/Latino community to increase education on Alzheimer's as well as address stigma of dementia diseases within the community. The emphasis on building multicultural alliances and growing trust between communities and advocates is crucial to progress in inclusion and diversity. The amount of time and effort invested by advocates should reflect on the strength of the relationship. My hope is that we see a deeper investment in community advocacy and trust building.
