



October 12, 2023

Monica N. Feit, PhD, MPH  
Executive Director

National Academies of Sciences, Engineering, and Medicine, Health and Medicine Division  
500 Fifth Street NW  
Washington, DC 20001

Dear Dr. Feit:

The National Down Syndrome Society (NDSS) empowers individuals with Down syndrome and their families by driving policy change, providing resources, engaging with local communities, and shifting public perceptions. We write today to share feedback on the National Academies of Sciences, Engineering, and Medicine's (NASEM) recent announcement of committee members for the consensus study "Research Priorities for Preventing and Treating Alzheimer's Disease and Related Dementias."

We appreciate NASEM's consideration of our organization's nominations, Dr. Michael Rafii, Professor of Clinical Neurology at the Keck School of Medicine and Medical Director of the Alzheimer's Therapeutic Research Institute (ATRI), and Dr. Liz Head, Professor and Vice Chair for Research, Department of Pathology and Laboratory Medicine at the University of California, Irvine. We understand that NASEM must employ a rigorous and selective process for identifying committee membership, however, **we are disappointed that there was not a single committee member chosen that has expertise in supporting, researching, or treating individuals with Down syndrome and Alzheimer's disease.**

Individuals with Down syndrome are uniquely situated in the Alzheimer's landscape because they have an extra copy of chromosome 21. The 21st chromosome carries the amyloid precursor protein (APP) gene, which is strongly associated with the formation of amyloid peptides and plaques, a hallmark of Alzheimer's disease. As a result, individuals with Down syndrome have an elevated lifetime risk – higher than 90% – for developing Alzheimer's disease with the onset of symptoms coming earlier and progressing faster than in the general population.<sup>1</sup> In fact, Alzheimer's disease is the number one cause of death for individuals with Down syndrome.<sup>2</sup>

There is no group or subpopulation that is more impacted by Alzheimer's disease than the Down syndrome community. By not including an expert on the cooccurrence of Down syndrome and Alzheimer's disease on the consensus study committee, a community that needs this research most

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<sup>1</sup> McCarron, M., McCallion, P., Reilly, E., Dunne, P., Carroll, R., & Mulryan, N. (2017). A prospective 20-year longitudinal follow-up of dementia in persons with Down syndrome. *Journal of intellectual disability research : JIDR*, 61(9), 843–852. <https://doi.org/10.1111/jir.12390>

<sup>2</sup> Hithersay, R., Startin, C. M., Hamburg, S., Mok, K. Y., Hardy, J., Fisher, E., Tybulewicz, V., Nizetic, D., & Strydom, A. (2019). Association of Dementia With Mortality Among Adults With Down Syndrome Older Than 35 Years. *JAMA neurology*, 76(2), 152–160. <https://doi.org/10.1001/jamaneurol.2018.3616>



could potentially be excluded from its focus, findings, and impact. **We urge you to reconsider the committee nominations and invite a researcher or clinician with expertise in the cooccurrence of Down syndrome and Alzheimer's disease to the committee.**

We are deeply appreciative of the work of NASEM in researching the prevention and treatment of Alzheimer's disease and related dementias and the opportunity for community to stakeholders to nominate and provide feedback on the consensus study committee membership. We hope to work collaboratively with NASEM to ensure that the committee membership is reflective of the communities who need this research most.

Best,

A handwritten signature in black ink that reads "Kandi Pickard". The signature is fluid and cursive, with a large, looping "O" at the end.

Kandi Pickard  
President and CEO  
National Down Syndrome Society