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My name is Sean Feely, and I am the Director of Advocacy & Public Policy at the National Down Syndrome Society (NDSS). We are grateful for the opportunity to provide comments on the unique impact of Alzheimer's disease on individuals with Down syndrome and the need to include this community in the work of the Advisory Council on Alzheimer's Research, Care, and Services.

Down syndrome occurs when an individual has a third copy of chromosome 21 instead of the typical two. Chromosome 21 also carries genes which are strongly associated with the formation of amyloid peptides and plaques that are a hallmark of Alzheimer's disease. In fact, individuals with Down syndrome have a higher than 90% lifetime risk for developing Alzheimer's disease, and the disease is the number one cause of death for adults with Down syndrome. The average age of onset is lower, and the disease also progresses faster than in the general population. Simply put, Alzheimer's disease has a devastating and disproportionate impact on the Down syndrome community.

While historically individuals with Down syndrome have been underrepresented with respect to Alzheimer's disease conversations, clinical trials, coverage determinations, and other efforts, change is underway. NDSS is grateful to this council for finalizing recommendations in September 2024 that reflected an unprecedented inclusion of the Down syndrome community. The council provided recommendations specific to the Down syndrome population related to: education and awareness campaigns; early detection and diagnosis; risk reduction strategies; research into fundamental biological processes and disease mechanisms; long-term care data and supports; and support for caregivers.

NDSS was also proud to work with Congress on the *NAPA Reauthorization Act* (P.L. 118-92), which expanded the number of non-federal members on the council from 12 to 15, created a new seat to represent an underserved population with an elevated lifetime risk of developing Alzheimer's disease, and made explicit reference to the Down syndrome community as such an underserved community. We strongly recommend that a representative of the Down syndrome community be included on the council.

We support the vital work and mission of this council and urge you to continue the important focus on the Down syndrome community's unique needs related to Alzheimer's disease research, education, diagnosis, clinical care, caregiving, and more.

NDSS stands ready to work with you to foster transformational change for the Down syndrome community. Thank you.

Sean Feely
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National Down Syndrome Society