



January 13, 2025

Good afternoon and thank you for the opportunity to speak with you today. My name is Margot Rhondeau, and I am the Senior Director of Health and Wellness at the National Down Syndrome Society.

Over the past several years, we have worked to ensure that someone from the Down syndrome community addresses this council to share how Alzheimer's disease profoundly impacts our community. Researchers, physicians, family members, and self-advocates have spoken here on a variety of topics related to Down syndrome-associated Alzheimer's disease (DSAD). We are deeply grateful that this council has listened and responded by increasing the inclusion of Down syndrome in your work. However, the reality remains that without intentional inclusion across each of the NAPA Council's six goals, our community will continue to face the challenges of exclusion and inequity.

Everyone here agrees: Alzheimer's disease is devastating. For individuals receiving the diagnosis, as well as for their families and caregivers. In my current position, I spend a good amount of time supporting families who navigate the daily challenges of DSAD. These families manage the heartbreaking symptoms of the disease while mourning the gradual loss of the person they once knew.

As the mother of a seven-year-old daughter with Down syndrome, this isn't just professional for me—it's personal. I live every day knowing that one day this will likely be my reality. My baby girl. For the past seven years, I've dedicated my life to ensuring that she has access to the therapies, opportunities, and resources to thrive and reach her fullest potential. Yet, I do this with the knowledge that one day she may lose all of it. Every skill we've worked so hard to achieve will be diminished through the devastating onset of Alzheimer's disease.

This isn't just my nightmare; it's the shared nightmare of every parent in the Down syndrome community. Individuals with Down syndrome face a staggering 90% lifetime risk of developing Alzheimer's disease. Think about that for a moment—90%. It is a reality that we cannot ignore.

Today, we stand at a pivotal moment in history. Scientific advancements have brought us closer than ever to the possibility of preventing Alzheimer's disease. I believe in the brilliance and dedication of researchers working toward a cure. But how devastating would it be if these breakthroughs became available to the general public, yet excluded my daughter and the 200,000+ people living with Down syndrome in the United States?

I am here today to ask you, as leaders and decision-makers, to ensure this doesn't happen. As treatments and cures are developed, we must guarantee that they are accessible to everyone—including those with Down syndrome.

My specific ask is that the newly created seat on the NAPA Council for a community disproportionately affected by Alzheimer's disease be designated for the Down syndrome community. Why? Because their lives are just as valuable. Their futures matter just as much. They do not deserve to die from Alzheimer's disease.

Together, we have the power to create a world where no one is left behind. Please help us ensure that the promise of a cure for Alzheimer's disease is a promise kept for all.

Thank you,

Margot Rhondeau