

January 22, 2024

Hi, my name is Dana Sciullo, and I am so thankful for the opportunity to speak today.

I come to you with a unique perspective. Professionally, I am the Health Programs Coordinator for the National Down Syndrome Society. I lead or assist with all the health and wellness related programming, resource creation, events, and advocacy. Many of these are related to Alzheimer's disease. The overall lifetime risk of developing Alzheimer's disease is more than 90% for individuals with Down syndrome. This is the devasting reality for families across the country and world.

NDSS continually hears from desperate families and individuals looking for treatments and a cure for Alzheimer's disease. To help address this, we produced a guidebook and hosted a webinar last month on Down syndrome and Alzheimer's disease. Both can be accessed through our website: ndss.org.

But all of that is only part of the reason I'm here today. The most important reason is Anthony.

Anthony loves to bowl, go to restaurants, do arts and crafts, hunt and fish, see his friends, and work at his job assisting with car oil changes. He spends his spare time exchanging handwritten letters with elderly community members who are ill or lonely, all of whom have grown to love him. Anthony is not just one of the estimated 250,000 Americans with Down syndrome. He's my best friend. He's my only sibling. He's my little brother.

When Anthony was 23 years old, he began having seizures. As part of his medical care, he received scans of his brain. The doctor was grave when they told us Anthony's brain was already showing visible plaque deposits, signs of early Alzheimer's disease. My parents cried as they talked about it in hushed voices later when they thought I couldn't hear.

Now, Anthony is aware of his high risk of developing Alzheimer's disease. He is watching our grandmother progress through each increasingly horrifying stage of the disease. Sometimes, he asks if that is what it will be like for him. Each time, I rack my brain to find an answer that includes hope. The best I've come up with is to tell him I am doing everything in my power to keep that from happening.

Today, I'm asking you to do everything in your power to give Anthony, and the thousands of other individuals who have Down syndrome, hope for a future free from the devasting effects of Alzheimer's disease. This can be done by increasing access to quality clinical care by specifically discussing Down syndrome and Alzheimer's disease in medical school curricula, increasing funding for Down syndrome and Alzheimer's disease research, encouraging inclusion in clinical trials for Alzheimer's disease interventions, granting access to Alzheimer's disease treatments which are covered by insurance, and educating long term care facilities about serving individuals with Down syndrome and Alzheimer's disease.

On behalf of Anthony, my family, and the many Americans who share our lived experience, thank you for your time, the work you do, and the work you will continue to do to fight this disease.

Dana Sciullo National Down Syndrome Society Health Programs Coordinator