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Hello. I am the Manager of Grassroots Advocacy at the National Down Syndrome Society. I am also the first registered lobbyist with Down syndrome.

When I was born 35 years ago, the life expectancy for a person with Down syndrome was only 30 years. Now the life expectancy is about 60 years. Thankfully, medical science has advanced and allowed me the opportunity to live a long and productive life.

However, as you may know, the vast majority of individuals with Down syndrome will experience the brain changes associated with early onset Alzheimer's disease. Many of these individuals will lose the skills and abilities they worked so hard to achieve and will require increasing assistance from others to care for themselves.

I have a friend who is currently experiencing early onset Alzheimer's disease and deteriorating quickly, and it is a scary reminder of what could happen in the future to me and others if we don't make discovering a treatment and cure for Alzheimer's disease for those with Down syndrome a priority. I was thrilled to hear drugs that slow the progression of Alzheimer's disease have begun to be approved by the FDA. However, it is also discouraging to hear that no individuals with Down syndrome were included in the safety trials. Because of that, physicians will not be able to confidently prescribe this potentially life-extending medication to individuals with Down syndrome despite it being approved for the general population.

It is vital that individuals with Down syndrome are given the chance to be included in clinical trials for Alzheimer's disease so they too can have safe access to the newest and most effective drug treatments for Alzheimer's disease.

Thank you for your continued support as we work to improve our community's access to accurate and timely diagnosis, care, and inclusion in research. Let's continue working to make healthcare equitable for everyone.

Kayla McKeon
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Manager of Grassroots Advocacy