

Good afternoon,

My name is Charlotte Woodward. I am an adult white woman with brown hair sitting in front of a white wall. I work at the National Down Syndrome Society as the Community Outreach Associate. NDSS is the leading human rights organization for all individuals with Down syndrome.

At this Council's meetings over the past year, you've heard from my colleagues at NDSS and others in the Down syndrome community about the genetic link between Down syndrome and Alzheimer's disease. You've heard that, at the population level, people with Down syndrome are more likely to develop Alzheimer's disease than others who have two copies of chromosome 21 instead of three. You've heard that no one fully understands why. You've heard that more research is needed and have been asked to form a subcommittee focused on improving supports for people with intellectual and developmental disabilities.

What you haven't heard yet is just how much adults with Down syndrome are capable of. As an adult with Down syndrome myself, I believe very deeply in breaking down myths and misconceptions about people who have Down syndrome.

I recently graduated from George Mason University, summa cum laude, with a Bachelor of Arts in Sociology with a concentration in Inequality and Social Change. My studies and my work perfectly complement each other. As a budding sociologist, I examine the structural and systemic inequalities in society that affect the lives of people with disabilities, and as an advocate, I use this knowledge to raise awareness about them and to affect positive change.

As part of my job at NDSS, I lobby Congress and federal agencies on behalf of the Down syndrome community. I have a bill named after me – the Charlotte Woodward Organ Transplant Discrimination Prevention Act – which would prohibit discrimination against all people with disabilities in the organ transplant process and make it easier for health care providers to understand what they can and cannot do. My bill has bipartisan support in both chambers of Congress.

I am here to urge you, once again, to establish a subcommittee on the connection between Down syndrome and Alzheimer's disease. I am doing my very, very best to keep my own body active and healthy, and to keep my brain intellectually stimulated, to hopefully avoid Alzheimer's disease in the future, but I need you to do your very, very best to investigate the association between the two conditions so that people with Down syndrome can live their lives free from Alzheimer's disease and to help make sure we get the best care if we do develop symptoms.

Thank you so very much for your time and your consideration of this pressing need.

Charlotte Woodward Community Outreach Associate National Down Syndrome Society