



Monday, August 5, 2024

Thank you so much and thank you all for having me. My name is Ryan Rotundo. I am the Director of Programs for the National Down Syndrome Society. I also like to share that I am the sibling of an amazing young woman with Down syndrome named Nicole. I won't tell you... well, I'll tell you her age. She usually fusses at me for this. We celebrated her 40th birthday in January and the first time, celebrating her birthday, knowing what I now know about the lifetime risk - the 90% lifetime risk - of individuals with Down syndrome developing Alzheimer's, it had a little bit of a different sense for me.

Many of our birthdays, as I'm sure you're familiar, are celebrated and there's lots of hope and excitement. This is the first year that, celebrating my sister's birthday, we sort of starting to think about some of the other issues that can come as these dates continue to roll by.

As Nancy has shared, individuals with Down syndrome are at a 90% increased risk for developing Alzheimer's. That is because of the genetic coding that is on the 21st chromosome. Having an extra copy of that chromosome makes individuals with Down syndrome more susceptible to this horrible disease.

The National Down Syndrome Society wants to applaud the robust inclusion of Down syndrome, with more than a dozen mentions in the council's draft recommendations. We want to also state that our community is committed to working with the council and HHS to see these recommendations implemented. The National Down Syndrome Society will continue to work with this council to see these recommendations implemented so that individuals and families continue to celebrate with hope and not worry and concern about what's ahead.

We thank you so much for this time and we ask that you would continue to move these pieces forward.

Thank you so much.

Ryan Rotundo

Director of Programs

National Down Syndrome Society