



Monday, October 21, 2024

Good afternoon, everyone. Thank you all for being here today and for this opportunity to provide a public comment. My name is Anna Fedewa, and I am the Senior Manager of Government Relations at the National Down Syndrome Society (NDSS). Today I have the privilege of celebrating alongside you as several critical pieces of legislation have been signed into law – the NAPA Reauthorization Act and the Alzheimer’s Investment and Accountability Act. NDSS had been an enthusiastic supporter of both pieces of critical legislation, but I would like to focus my time on the NAPA Reauthorization Act which, as enacted, includes amendments that more explicitly and robustly include the Down syndrome community in the work of this council and subsequently of the National Alzheimer’s Plan.

As you all are well aware, research supports how devastatingly and disproportionately this disease impacts individuals with Down syndrome. Nonetheless, for years the Down syndrome community has been excluded from conversations, clinical trials, coverage determinations, and efforts to better understand and fight this terrible disease. The recent work of this council and the passage of the NAPA Reauthorization marks a significant evolution in this historical underrepresentation. In September, this council finalized your 2024 recommendations which included unprecedented inclusion of the Down syndrome community who were explicitly mentioned over a dozen times in the final recommendations. On the heels of this monumental progress came the passage of the NAPA Reauthorization which includes language that explicitly includes the Down syndrome community as an underserved population and creates a seat on the council for “1 representative from a historically underserved population whose lifetime risk for developing Alzheimer’s is markedly higher than that of other populations.” We believe a representative from the Down syndrome community is well poised to hold this seat and contribute to the valuable work of this council. We hope that when the time comes to appoint this seat, a representative nominated by the Down syndrome community will be invited to join the council.

The progress this council and the United States Congress has made gives us great hope. My work at NDSS is personal to me as I have many friends, former classmates, and close family friends with Down syndrome. While I will never truly understand what it is like to be a parent or a sibling of someone whose life is changed by this disease, I do have the perspective of someone who never wants to see their childhood best friend or their college classmate who once shone so brightly have their light dimmed by this disease. Thank you for giving me and our entire community hope that these bright lights can keep shining. While we celebrate this great progress, I think we can all agree there is still so much work to be done. NDSS and the Down syndrome community look forward to continuing this important work alongside you all. Thank you.

Anna Fedewa
Senior Manager of Government Relations
National Down Syndrome Society (NDSS)