



The Honorable Susan Collins  
413 Dirksen Senate Office Building  
Washington, DC 20510

**RE: NDSS Support of S. 133, the NAPA Reauthorization Act**

Dear Senator Collins:

The National Down Syndrome Society (NDSS) empowers individuals with Down syndrome and their families by driving policy change, providing resources, engaging with local communities, and shifting public perceptions. We strongly support the passage of S. 133, the NAPA Reauthorization Act, as amended by the proposed manager's amendment, to further support the coordination of federal planning and programs.

Since its passage in 2011, the National Alzheimer's Project Act (NAPA) has resulted in significant advancements in the fight against Alzheimer's disease and other dementias through a coordinated National Plan and the inception of the Advisory Council on Alzheimer's Research, Care, and Services. Reauthorization of this legislation is critical to ensuring the continuation of advancements in Alzheimer's diagnoses, treatment and care.

Furthermore, the inclusion of the Down syndrome community and other underrepresented groups reflected in the manager's amendment is an important step forward, especially for our community. Individuals with Down syndrome are uniquely situated in the Alzheimer's landscape because they have an extra copy of chromosome 21. The 21st chromosome carries the amyloid precursor protein (APP) gene, which is strongly associated with the formation of amyloid peptides and plaques, a hallmark of Alzheimer's disease. As a result, individuals with Down syndrome have an elevated lifetime risk for developing Alzheimer's disease, with the onset of symptoms coming earlier and progressing faster than in the general population. In fact, Alzheimer's disease is the number one cause of death for individuals with Down syndrome.

Reauthorizing NAPA with these amendments that specifically include and support the Down syndrome community and other underrepresented groups will ensure the continuation of the important work guided by this bill while also representing specific populations that are disproportionately impacted by Alzheimer's disease.

NDSS strives to ensure all individuals with Down syndrome are guaranteed their human rights and valued by a more inclusive society. The passage of S. 133 will make important progress toward both of those goals. We urge Congress to reauthorize NAPA, as amended, and we thank you for your leadership regarding this important piece of legislation.

Sincerely,

A handwritten signature in black ink that reads "Kandi Pickard". The signature is fluid and cursive, with a large loop at the end of the name.

Kandi Pickard  
National Down Syndrome Society  
President & CEO