



February 12, 2024

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

The Honorable Shelley Moore Capito
170 Russell Senate Office Building
Washington, DC 20510

The Honorable Jerry Moran
521 Dirksen Senate Office Building
Washington, DC 20510

The Honorable Lisa Murkowski
522 Hart Senate Office Building
Washington, DC 20510

The Honorable Christopher Smith
2373 Rayburn House Office Building
Washington, DC 20515

The Honorable Edward Markey
255 Dirksen Senate Office Building
Washington, DC 20510

The Honorable Mark Warner
703 Hart Senate Office Building
Washington, DC 20510

The Honorable Robert Menendez
528 Hart Senate Office Building
Washington, DC 20510

The Honorable Debbie Stabenow
731 Hart Senate Office Building
Washington, DC 20510

The Honorable Paul Tonko
2369 Rayburn House Office Building
Washington, DC 20515

The Honorable Maxine Waters
2221 Rayburn House Office Building
Washington, DC 20515

RE: NDSS letter of support for the Alzheimer's Accountability and Investment Act (H.R. 620/S. 134)

Dear Senators Collins, Markey, Moore Capito, Warner, Moran, Menendez, Murkowski, and Stabenow, Congressmen Smith and Tonko and Congresswoman Waters:

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 write today in support of the *Alzheimer's Accountability and Investment Act* (H.R. 620/S. 134) which would ensure Alzheimer's and dementia research is funded at the levels needed to achieve the goals in the National Plan to Address Alzheimer's Disease.

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, upwards of 90%, 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.



Given the critical nature of this disease to the Down syndrome community, NDSS has facilitated sustained engagement with the National Alzheimer's Project Act (NAPA) Council which oversees the National Plan. An NDSS staff member or a representative of the Down syndrome community has shared [remarks](#) at every quarterly NAPA council meeting since October 2021. Furthermore, NDSS has also played an active role in advocating for the NAPA Reauthorization Act, as amended by the Senate HELP Committee, to ensure the important work of the NAPA council continues and is inclusive of the Down syndrome community. Our unequivocal support of the Alzheimer's Accountability and Investment Act builds upon these efforts.

Ensuring that Alzheimer's and dementia research is funded at the levels needed to achieve the goals in the National Plan to Address Alzheimer's Disease is paramount to supporting communities experiencing Alzheimer's disease and related dementia at markedly higher rates, such as the Down syndrome community. We urge Congress to pass the Alzheimer's Accountability and Investment Act 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.

Kandi Pickard
President and CEO
National Down Syndrome Society