national down syndrome society
ndss®

July 18, 2025

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

The Honorable Mike Carey
1433 Longworth House Office Building
Washington, DC 20515

The Honorable Michael Bennet
261 Russell Senate Office Building
Washington, DC 20510

The Honorable Linda Sánchez
2309 Rayburn House Office Building
Washington, DC 20515

Dear Senators Capito and Bennet and Representatives Carey and Sánchez:

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 strong support of the passage of the *Credit for Caring* Act (S. 925/H.R. 2036), which would create a new tax credit of up to $5,000 for working family caregivers of certain individuals with long-term care needs. Individuals with Down syndrome often require high levels of daily assistance and financial support, leading their loved ones to face steep caregiving costs. These costs are further exacerbated by a higher frequency and earlier onset of Alzheimer's disease in the Down syndrome community. The Credit for Caring Act would help alleviate the financial challenges of caring for a loved one that many family members of people with Down syndrome face.

Down syndrome occurs when an individual has a full or partial third copy of chromosome 21 instead of the typical two. Chromosome 21 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. Having an extra copy of chromosome 21 puts individuals with Down syndrome at a higher than 90% lifetime risk for developing Alzheimer's disease, which is the number one cause of death for individuals with Down syndrome. The average age of onset of the disease for individuals with Down syndrome is 58 years old, compared to 65 years old for the general population.

As the life expectancy of individuals with Down syndrome grows, caregivers of loved ones with Down syndrome reckon with increasing medical costs and limited options for support. Family caregivers spend thousands of dollars per year on out-of-pocket caregiving expenses. The frequent occurrence of Alzheimer's disease among people with Down syndrome, along with its relatively early onset, means that loved ones of people with Down syndrome are also disproportionately impacted by the caregiving costs associated with Alzheimer's disease. This financial burden is compounded by the fact that individuals with both Down syndrome and Alzheimer's are often cared for by aging parents or siblings, who are either saving for their own retirement or supporting their own young families. Additionally, many memory or long-term care centers will not accept individuals with Down syndrome due to their dual diagnosis, leaving caregivers with limited options.

Caregivers of people with Down syndrome deserve support and financial security as they navigate the increased challenges of caring for aging loved ones and early onset and increased occurrence of Alzheimer’s. By passing the Credit for Caring Act, Congress can take an important step toward acknowledging and alleviating the challenges that working family caregivers face.

NDSS strives to ensure all individuals with Down syndrome are assured their human rights and valued by a more inclusive society. The well-being and financial stability of caregivers play a pivotal role in this mission. We urge Congress to take action and provide working family caregivers with crucial relief, and we thank you for your leadership regarding this important piece of legislation.

Sincerely,

Kandi Pick

Kandi Pickard
President and CEO
National Down Syndrome Society