



NAPA Reauthorization Act (S. 133/H.R. 619)

Legislative Request

Please vote **YES** on the House and Senate floor.

Background

People 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.

Unfortunately, Alzheimer's disease is commonly misdiagnosed in patients with Down syndrome due to some observable traits that are common to both conditions – an issue called diagnostic overshadowing. This issue, combined with a general lack of education about Down syndrome provided to our nation's medical professionals, makes it likely that individuals with Down syndrome will be left out of clinical trials for drugs to treat or prevent Alzheimer's disease.

Older Americans who develop Alzheimer's disease frequently receive care from their children, whereas people with Down syndrome are typically provided care by their parents. For parent caregivers, this reality can cause uncertainty of who will care for their children as they themselves also age. Many memory or long-term care centers will not accept individuals with Down syndrome due to the age of the person with Down syndrome and their Alzheimer's diagnosis. Siblings will frequently step in to provide care when their parents are no longer able, but this transition often necessitates a move to a new state and can result in the loss of vital government benefits such as those for home and community-based services.

Bill Summary

Introduced by Representatives Paul Tonko (D – NY), Christopher Smith (R – NJ), and Maxine Waters (D – CA) in the House and Senators Susan Collins (R – ME), Mark Warner (D – VA), Shelley Moore Capito (R – WV), Edward Markey (D – MA), Jerry Moran (R – KS), Robert Menendez (D – NJ), Lisa Murkowski (R – AK), and Debbie Stabenow (D – MI) in the Senate, the National Alzheimer's Project Act (NAPA) Reauthorization Act would build upon efforts to address Alzheimer's disease and related dementia through the coordination of federal planning and programs.

Important Information

- The bill has broad bipartisan support in both chambers.
- The bill, as amended, includes critical language to ensure the Down syndrome community is more robustly included in the work of the National Alzheimer's Plan.
- The bill has passed the Senate HELP Committee and the House Energy and Commerce Committee.

Additional Considerations

Following the successful passage of the NAPA Reauthorization Act, NDSS urges Congress to focus their attention on the following critical priorities:

Increasing Access to Diagnostic Care and Treatment

Congress must ensure that insurance coverage, especially at the Centers for Medicare & Medicaid Services, provides meaningful access to diagnostic care and treatment for individuals with Down syndrome, on par with care received by members of the general public. Since people with Down syndrome often show symptoms of Alzheimer's-related dementia earlier than others, threshold ages must be lowered as necessary, and key government healthcare benefits must be portable across state lines.

Supporting Caregivers

Congress must ensure that families have evidence-based training to provide high-quality care to their loved ones, community-based supports to allow them to care for themselves, and information necessary to prepare adequately for the financial impact of providing care. Congress should also consider ways in which memory care and long-term care centers can be more adequately supported in providing care to populations who experience Alzheimer's disease and related dementia at an earlier age and those with both Down syndrome and Alzheimer's disease.

For more information, please contact Anna Fedewa, National Down Syndrome Society Senior Manager of Government Relations, at afedewa@ndss.org