



Inclusion of the Down Syndrome Community in Alzheimer's Disease Initiatives

Legislative Request

Please support the inclusion of the Down syndrome community in Alzheimer's Disease initiatives by supporting:

- Efforts to increase inclusion in research and development of treatments, such as the bipartisan Ensuring Pathways to Innovative Cures (EPIC) Act (S. 832/H.R. 1492)
- Efforts to increase access to diagnostic care and treatment
- Efforts to better support caregivers of individuals with Down syndrome and Alzheimer's disease by providing training and respite care support

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 critical opportunities to further understand, 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.

Policy Considerations

Inclusion in Research

Last year, Congress passed the NAPA Reauthorization Act, which extends the National Alzheimer's Project through 2035. This project supports coordination of federal planning, programs, and other efforts to address Alzheimer's disease. The NAPA Reauthorization Act also included language to include individuals with Down syndrome and other developmental disabilities in these efforts. Given the connection between the 21st chromosome and Alzheimer's, the Down syndrome community should be included in research efforts, including trials and studies. Individuals with Down syndrome have a greater likelihood of developing Alzheimer's than their non-disabled peers. Given this greater risk, the Down syndrome community should have a seat at the table to find a cure for Alzheimer's.

Removing Barriers to the Development of Potential Treatments

The Inflation Reduction Act of 2022 (IRA) included several provisions to help lower the cost of healthcare for American families but it also included a provision that treats small-molecule medicines — drugs that come in simple forms such as pills, tablets, and patches — differently than more invasive drugs and treatments. This “pill penalty” negatively impacts individuals with Down syndrome who often rely on and benefit greatly from small-molecule drugs. Unlike large-molecule drugs such as biologics, these medications can cross the blood-brain barrier, targeting the root causes of dementia and present one possible treatment option that could have a profound impact on individuals with Down syndrome and Alzheimer's Disease and related dementia. We urge Congress to pass the bipartisan *Ensuring Pathways to Innovative Cures (EPIC) Act* (S. 832/H.R. 1492) which would ensure that two equally important and impactful types of drugs – small and large molecule drugs – are treated equally under the law and the development of one is not prioritized over the other.

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 policy@ndss.org