



February 12, 2024

The Honorable Brett Guthrie  
2434 Rayburn House Office Building  
Washington, DC 20515

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

The Honorable Christopher Smith  
2373 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 Building Our Largest Dementia (BOLD) Infrastructure for Alzheimer's Act of 2024 (H.R. 7218)**

Dear Congressmen Guthrie, Tonko, Smith, 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 *Building Our Largest Dementia (BOLD) Infrastructure for Alzheimer's Act of 2024* (H.R. 7218) which would extend critical funding for our country's Alzheimer's disease and related dementia infrastructure.

Since Congress first passed the BOLD Infrastructure for Alzheimer's Act into law in 2018 (P.L. 115-406), there have been significant advancements in areas such as early detection and diagnosis of Alzheimer's disease and related dementia, risk reduction, prevention of avoidable hospitalizations, and supporting dementia caregiving. The importance of these investments to the Down syndrome community cannot be understated.

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.

Extending the work of the BOLD infrastructure would continue to strengthen our country's funding and support to state, local, and tribal public health departments to ensure that Americans with Alzheimer's disease and dementia who most need support, such as the Down syndrome community, can continue to access critical supports and resources. We urge Congress to pass the Building Our Largest Dementia (BOLD) Infrastructure for Alzheimer's Act of 2024 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