



**CONSORTIUM FOR CITIZENS  
WITH DISABILITIES**

The Honorable Mitch McConnell  
Majority Leader  
United States Senate  
Washington, DC 20510

The Honorable Charles Schumer  
Democratic Leader  
United States Senate  
Washington, DC 20510

The Honorable Nancy Pelosi  
Speaker  
United States House of Representatives  
Washington, DC 20515

The Honorable Kevin McCarthy  
Minority Leader  
United States House of Representatives  
Washington, DC 20515

Dear Leader McConnell, Leader Schumer, Speaker Pelosi and Leader McCarthy:

The undersigned members of the Consortium for Citizens with Disabilities (CCD) and allies write as more than half the members of the House and Senate have co-sponsored the ALS Disability Insurance Access Act of 2019 (S. 578 and H.R. 1407). CCD is the largest coalition of national organizations working together to advocate for federal public policy that ensures the self-determination, independence, empowerment, integration and inclusion of children and adults with disabilities in all aspects of society. As Congress considers bringing this legislation to the floor, we urge Congress to eliminate this waiting period for all people with disabilities.

Currently, people with disabilities who have gone through the intensive review process for Social Security Disability Insurance (SSDI) must wait an additional five months from the onset of disability for SSDI benefits to become payable. This delay causes significant hardship for people with disabilities and their families. People can lose their housing, health insurance, or face other financial crises, often resulting in reliance on other public benefits. For conditions with rapid onsets, such as metastatic breast and other aggressive cancers, traumatic injuries, heart attacks, and strokes, the delay can result in death before benefit eligibility begins. There is also an additional two-year waiting period before Medicare coverage, which creates additional challenges.

We strongly support bills that eliminate both the five-month waiting period for SSDI and the two-year waiting period for Medicare for all people with disabilities, such as the Stop the Wait Act (S. 2496 and H.R. 4386). We will also note that the waiting periods are complicated for the Social Security Administration to administer, especially when the SSDI waiting period necessitates payment of Supplemental Security Income (SSI) during the five-month wait. This complication will increase if specific conditions do not have to wait and others do.

Bills that only fix the problem for some people who meet the strict eligibility standards for SSDI<sup>1</sup> are likely to lead to interest groups requesting waiver of wait periods for other impairments. We urge Congress to enact broader fixes. To leave millions of people with disabilities waiting for their earned benefits is unfair and will result in unnecessary deaths.

We look forward to working with Congress on this important issue. Please do not hesitate to contact Stacy Cloyd ([stacy.cloyd@nosscr.org](mailto:stacy.cloyd@nosscr.org)) or Bethany Lilly ([lilly@thearc.org](mailto:lilly@thearc.org)) with any questions or to arrange a meeting.

Sincerely,

Advocacy and Training Center  
Alliance for Retired Americans  
American Association on Health and Disability  
American Association on Intellectual and Developmental Disabilities  
American Kidney Fund  
Arthritis Foundation  
Autistic Self Advocacy Network  
Brain Injury Association of America  
Center for Public Representation  
Charlotte Center for Legal Advocacy  
Coalition on Human Needs  
Conquering CHD  
Cystic Fibrosis Foundation  
Economic Policy Institute  
Epilepsy Foundation  
Glut1 Deficiency Foundation  
Hemophilia Federation of America  
Justice in Aging  
Lakeshore Foundation  
Latinos For A Secure Retirement  
Lupus Foundation of America  
National Alliance on Mental Illness  
National Association of Councils on Developmental Disabilities  
National Association of Disability Representatives  
National Committee to Preserve Social Security and Medicare  
National Disability Rights Network (NDRN)  
National Down Syndrome Congress  
National Employment Law Project  
National Organization of Social Security Claimants' Representatives

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<sup>1</sup> Beyond the ALS Disability Insurance Access Act of 2019, these include the Metastatic Breast Cancer Access to Care Act (S.1374 and H.R. 2178), the Huntington's Disease Parity Act of 2019 (S. 1476 and H.R. 2770), and the Expedited Disability Insurance Payments for Terminally Ill Individuals Act of 2019 (S.2262 and H.R. 142).

Paralyzed Veterans of America  
Pulmonary Hypertension Association  
Social Security Works  
Special Needs Alliance  
The Arc of the United States  
United Spinal Association  
WA State Alliance for Retired Americans  
Women's Institute For A Secure Retirement