

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

The Honorable Nancy Pelosi Speaker United States House of Representatives Washington, DC 20515 The Honorable Charles Schumer Democratic Leader United States Senate Washington, DC 20510

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 SSDI¹ 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) or Bethany Lilly (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

¹ 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 III 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