



September 8, 2020

The Honorable Nancy Pelosi
Speaker of the House
1236 Longworth House Office Building
Washington, DC 20515

The Honorable Kevin McCarthy
House Republican Leader
2468 Rayburn House Office Building
Washington, DC 20515

Re: Schedule Vote on ALS Disability Insurance Access Act (H.R. 1407)

Dear Speaker Pelosi, Leader Hoyer, Leader McCarthy, and Whips Clyburn and Scalise:

The undersigned patient advocacy organizations represent the thousands of people living with amyotrophic lateral sclerosis (ALS) and their families in the United States. Together, we urge you to immediately schedule a vote to pass the ALS Disability Insurance Access Act (H.R. 1407), which recently surpassed the requisite 290 cosponsors to qualify for placement on the Consensus Calendar. The bill would waive the five-month Social Security Disability Insurance (SSDI) waiting period for people with ALS.

ALS is a unique progressive neurodegenerative disease that is 100 percent fatal. It takes about a year to confirm a diagnosis, there is no cure and average life expectancy is two to five years following diagnosis. People with ALS lose the ability to initiate and control muscle movement. As a result, they lose their jobs and employer-based insurance during the most challenging periods of their lives. Recognizing the devastating nature of ALS, Congress passed bipartisan legislation in 2000 that waived the two-year waiting period for Medicare.

Unfortunately, people with ALS who have contributed to Social Security during their work years must wait five months to receive SSDI benefits that help pay for medical care, food and housing. In addition, Medicare benefits are delayed as well during the five-month wait for SSDI, despite the clear congressional intent that people with ALS should receive immediate access to Medicare benefits.

The Social Security Administration estimates that between 1,500 and 2,000 SSDI-eligible people with ALS are impacted by the SSDI waiting period annually. The Congressional Budget Office informally estimates the cost of the bill at \$328 million over a 10-year period, including partial offsets.

Time works against people living with ALS. It is essential that we lift the five-month SSDI waiting period and allow immediate access to disability benefits for those who have received an ALS diagnosis. We respectfully request that H.R. 1407 be immediately scheduled for a vote.

Please contact Abram Bieliauskas (abieliauskas@alsa-national.org or 202-464-8645), Associate Director, Government Affairs at The ALS Association if you have any questions. Thank you for your consideration of this urgent request.

Sincerely,

ALS Association
I AM ALS
Les Turner ALS Foundation
Muscular Dystrophy Association
Team Gleason

Cc:

The Honorable Steny Hoyer
The Honorable Jim Clyburn
The Honorable Steve Scalise