



Statement of Support for the ALS Disability Insurance Access Act

The above 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 co-sponsor and pass the bipartisan ALS Disability Insurance Access Act (H.R. 1407/S. 578). The bill would waive the five-month Social Security Disability Insurance (SSDI) waiting period for people with ALS. As of October 21, the bill has 200 cosponsors in the House and 50 in the Senate.

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, physicians treating people with ALS report that Medicare benefits are often mistakenly delayed as well during the five-month wait for SSDI.

There is strong bipartisan support for the ALS Disability Insurance Access Act. 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 \$270 million over a 10-year period.

The ALS Disability Insurance Access Act is currently being considered by the House Ways and Means and the Senate Finance Committees. We urge those committees, House and Senate leadership, and all members of Congress to take action and pass this legislation immediately.

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.