



ALS Disability Insurance Act of 2019 (H.R. 1407, S.578)

ALS is a quickly progressing disease. People diagnosed with ALS can't afford to wait to access the SSDI benefits they desperately need.

Currently, all people living with Amyotrophic Lateral Sclerosis (ALS) who qualify for Social Security Disability Insurance (SSDI) must wait five months before they can begin receiving these benefits.

To address this issue and provide relief for these individuals, Sen. Sheldon Whitehouse (D-RI), Sen. Tom Cotton (R-AR), Rep. Seth Moulton (D-MA), and Rep. Peter King (R-NY) introduced the ALS Disability Insurance Act in February 2019. The legislation would eliminate the five month waiting period for SSDI benefits for people living with ALS so that they can begin receiving these benefits immediately.

Because ALS can progress very quickly, it is essential that diagnosed individuals are able to access SSDI benefits as soon as possible. Congress has recognized the urgent need of the ALS community before when it voted in 2000 to waive the two year waiting period for Medicare eligibility for ALS patients.

The Muscular Dystrophy Association has led the way for innovations in ALS science and care for nearly 70 years. We have dedicated hundreds of millions of dollars to ALS research, and care for tens of thousands of people diagnosed with ALS and their families.

MDA urges every Member of Congress to co-sponsor the ALS Disability Insurance Act.

About ALS

ALS is a progressive neuromuscular disease that destroys muscle-controlling nerve cells called motor neurons.

It is estimated to affect 5 out of every 100,000 people in the United States.

Between 15,000 and 20,000 Americans are estimated to be living with ALS.

Onset of ALS symptoms usually occurs in late middle age or later, but it also can occur in young adults, as well as in the elderly.

Most cases are sporadic, meaning there is no family history of the disease.