



ALS Disability Insurance Access Act Reintroduced in 116th Congress

Bipartisan Legislation Eliminates Five-Month Waiting Period for SSDI Benefits for People Diagnosed with ALS

The ALS Disability Insurance Access Act was reintroduced in the 116th Congress this week as [S.578](#) in the Senate by Senator Sheldon Whitehouse (D-RI) and Senator Tom Cotton (R-AR). Representatives Seth Moulton (D-MA) and Peter King (R-NY) introduced the companion bill in the House as [H.R.1407](#). The bill was introduced with strong bipartisan support from 40 senators and 90 representatives.

Last year, thanks to your advocacy, the bill gained considerable momentum. Within three months of the 2018 National ALS Advocacy Conference, more than one-third of Congress supported the bill. Within seven months, for the first time ever, the bill was considered for passage through the Senate via unanimous consent.

Multiple research studies indicate that people who have served in the military are at far greater risk of developing ALS and dying from the disease than those with no history of military service.

The ALS Association is honored to work with more than 20,000 people with ALS annually, including active duty military and veterans, through our nationwide system of chapters.

“Over the course of a five-month waiting period, people living with ALS will have only experienced progressive loss of function and will have incurred significant expenses for care and treatment,” said Calaneet Balas, president and CEO of The ALS Association. “We urge Congress to pass this legislation and remove the arbitrary five-month waiting period that creates an unfair financial burden on people whose life expectancy is so tragically abbreviated. People with ALS have earned and should receive both Medicare and Social Security Disability Insurance benefits immediately. They simply don’t have months to wait.”

Senator Whitehouse said, “I am proud to co-sponsor this bill to eliminate the waiting period for those battling ALS. It takes tremendous courage from patients, family members, and friends to cope with an ALS diagnosis. I hope that as a simple act of humanity we can set aside bureaucratic considerations and allow Americans who face the extraordinary blow of this diagnosis to immediately receive the benefits they have earned.”

Senator Cotton said, “ALS is a progressive and disabling disease for which there is no cure. Those who suffer from this terrible disease endure enough pain, and they shouldn’t be subject to the usual waiting period for disability benefits—especially given their tragically short life expectancy.”

Representative Moulton said, “Nobody bravely fighting Lou Gehrig’s Disease should have to wait months for benefits that will help them confront the disease because of government red tape. Every American pays into Social Security with the idea that we have each other’s backs and that those benefits will become available to us when we need them—whether it is because of an ALS diagnosis, a disability or simply to help make ends meet in retirement. This bill will help our country keep that promise.”

Representative King said, “When battling an unforgiving and aggressive disease such as ALS, time is of the essence. That is why Congress must ensure that those diagnosed with this disease can immediately receive the SSDI benefits they have earned and try to mitigate the certain and devastating financial costs of their fight.”

There is a strong precedent for waiving the five-month waiting period before people with ALS receive access to SSDI benefits. In 2000, Congress recognized the unique features of ALS and passed a bipartisan bill waiving the standard two-year waiting period before people with the disease become eligible for Medicare.

Watch Mary Johnson, who has now lost 15 family members to the familial form of ALS, talk about why the five-month waiting period should be waived.

<https://www.youtube.com/watch?v=X2pXNcfPOjg>

Momentum continues to build: 40 Senators and 90 Representatives signed on as original cosponsors this Congress – a 900 percent increase in original cosponsors in the Senate and 190 percent increase in the House over the 115th Congress.

[Ask your members of Congress to cosponsor this bill today to keep the momentum going!](#)
For more information about The ALS Association’s legislative priorities for 2019, please visit bit.ly/2EfjkyF.