



ALS Advocates Take Action During Congressional Recess

With Congress home for the August recess, The ALS Association is redoubling its efforts to build upon momentum toward achieving a long sought policy goal – the elimination of a five month waiting period for Social Security Disability Insurance.

During the summer recess, ALS Association chapters are focused on completing in-district meetings with members of Congress who have not already cosponsored the ALS Disability Insurance Access Act and urging them to support this bill. By increasing the number of cosponsors on this bill, we increase the chances of passing the bill before the end of the 116th Congress.

Time works against people living with ALS. Because of the debilitating nature of the disease, people diagnosed with ALS lose their jobs and employer-based insurance during the most challenging periods of their lives. The financial burden of the disease is compounded by our current laws, which requires people diagnosed with ALS to wait five full months before they receive their Social Security Disability Insurance (SSDI) benefits. Every patient must wait regardless of the level of disability or how fast the Social Security Administration (SSA) approves their claim.

This is just one way the Association is fighting for better policy for people living with ALS, and a continuation of the work ALS advocates do.

“A measure of government and how it operates is how well it treats its most disabled citizens,” said Steve Kowalski, who was diagnosed with ALS in 2017 and who attended the 2019 National ALS Advocacy Conference. During our three days together, we learned about the latest ALS research, shared our challenges in living with this disease, and visited Capitol Hill to share our stories with members of Congress.

To watch a video about our 2019 Advocacy Conference, [click here](#).

Every day, policymakers at all levels of government make decisions that could affect funding for ALS research and programs that serve the ALS community. With the start of the 116th Congress came the opportunity to renew our advocacy efforts and educate the newly sworn in members of Congress about the impacts of this devastating disease.

Meetings with members of Congress held during the 2019 National ALS Advocacy Conference continue to pay dividends for all of our advocacy priorities, including the ALS Disability Insurance Access Act ([S.578/H.R.1407](#)). 34 representatives and 5 senators added their support by cosponsoring this bill in the weeks following the conference, joining the 150 representatives and 44 senators who cosponsored the bill in the first four months after its reintroduction.

To join your community in explaining the impact of the Social Security Disability Insurance (SSDI) five-month waiting period and urge your members of Congress to support this bill, [click here](#) to send a letter today. In raising our voices together, we can ensure that anyone diagnosed with ALS who has made contributions into Social Security throughout their working lives is able to access the benefits they are entitled to receive.