

FOR IMMEDIATE RELEASE

## ALS Community Comes Together to Urge Congress to Pass ALS Disability Insurance Access Act

*Through coordinated efforts of 20 ALS advocate groups,  
over 360 co-sponsors secured in both House and Senate*

**SKOKIE, IL** – Sept. 15, 2020 – This week, 20 ALS advocacy groups, including [the Les Turner ALS Foundation](#), collaborated to thank the more than 360 Congressional members from across the aisle who have co-sponsored the ALS Disability Insurance Access Act ([H.R. 1407](#) and [S. 578](#)), which would extend Social Security Disability Insurance (SSDI) benefits for patients living with ALS. The ALS community is now calling on Congress for swift passage of the legislation.

The coordinated campaign among local, regional and national ALS organizations drove progress in the past six months to attain Congressional support. The passing of the bill will provide ALS patients and their loved ones access to SSDI benefits without having to wait five months from the time of diagnosis – an eternity within the two-to-five-year life expectancy of the disease.

“We have been working together as an ALS community for several years to move this critical legislation forward,” said Les Turner ALS Foundation CEO Andrea Pauls Backman. “The time is NOW to pass the ALS Disability Insurance Access Act, which is vitally needed by so many living with ALS and their family members. We thank all of our advocacy partners in their dedicated efforts to secure the needed co-sponsors to move the bill to the House for a vote.”

The ALS advocacy groups who worked with Congress included:

- ALS Hope Foundation
- ALS ONE
- Answer ALS
- Augie's Quest to Cure ALS
- Brigance Brigade
- Compassionate Care ALS
- Every90Minutes Foundation
- Everything ALS
- Hope Loves Company
- I AM ALS
- Joe Martin ALS Foundation
- Les Turner ALS Foundation
- A Life Story Foundation
- Live Like Lou
- Muscular Dystrophy Association
- The Northeast ALS Consortium (NEALS)
- The Project ALS Therapeutics Core at Columbia
- Team Stevens Nation
- Team Gleason
- Your ALS Guide

The ALS community is grateful to each Representative and Senator supporting H.R. 1407 and S.578 during this critical moment for our nation. ALS is an enormous financial burden and it is crucial those living with ALS and their families have as much support as possible. Now, more than ever, it is imperative Congress passes H.R. 1407 and S. 578 and sends it to the President's desk for his signature.

### **About ALS**

ALS is a rapidly progressive, neuromuscular disease that causes muscle weakness in the arms and legs and causes difficulty speaking and swallowing. ALS can, in some cases, also cause changes in intellectual function, mood, behavior or personality. No two cases of ALS are the same and no two people living with ALS are exactly alike. The symptoms and progression of the disease can vary greatly. While technically considered a "rare disease," experts predict an individual's lifetime risk of acquiring ALS is about 1 in 300, by the age of 85.

### **About the Les Turner ALS Foundation**

Founded in 1977, the Les Turner ALS Foundation is one of the longest-serving independent ALS groups in the country. For over 40 years, we have taken an individualized approach to ensure each person living with the disease receives the best quality of care and access to the most promising therapies. We treat each person like family, supporting them every step of the way, and provide their loved ones with answers and encouragement.

Our Les Turner ALS Center at Northwestern Medicine is led by the most well-respected and successful clinicians and researchers in the field, advancing vital care and research in pursuit of life-enhancing treatments and a cure.

For more information, visit [lesturnerals.org](http://lesturnerals.org).

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