

Welcome to the very first edition of the ALS Congressional Newsletter! This issue provides updates on ALS-relevant legislation, highlights of what I AM ALS and the ALS advocacy community-at-large are doing to create a future free of neurodegenerative diseases, and a focus on what we can continue to deliver, together.

Milestones and Action Items

We've reached over 130 members in the House ALS Caucus, which was created June 2019 and 14 in the Senate ALS Caucus, which was created in January 2020. See the [full list here](#).

Join our first ALS Caucus call on April 29, 2020 to hear updates on what we're doing and how you can help end ALS. Invite to follow.

May is ALS Awareness Month and we are working on our engagement plan – check out a sneak peek of our collaborative campaign [here](#) – we will provide additional details on the ALS caucus call in April.

I AM ALS co-founder, Brian Wallach, also recently submitted a 2020 written testimony to the House Appropriations Subcommittee on Labor, Health and Human Services, Education and Related Agencies. [See the written testimony here](#).



ALS patients, caregivers, and advocates are visited by Senator Murkowski and Senator Braun at a More Than Our Stories event.



Brian Wallach, I AM ALS co-founder, testifies before Congress.

What You Can Do to Support the ALS Community Today

1. Raise awareness to double congressional funding for Department of Defense (DOD) ALS research from \$20 to \$40 million and again increase the National Institutes of Health (NIH) ALS research spending by at least \$20 million. [See the Appropriations Dear Colleague letter sent by Senator Coons and Senator Cassidy here](#), and by [Congressman Gallagher and Congressman Crow here](#).
2. Make real a funded expanded access program for ALS – providing people living with the disease a pathway to access safe, and potentially life-changing therapies ahead of FDA approval. [See the letter sent to the FDA commissioner, Dr. Steve Hahn, on March 6, 2020 by 41 members of Congress](#).
3. Work with all members of Congress to pass the [ALS Disability Insurance Access Act of 2019](#) bill to eliminate the waiting period for ALS patients and their families to receive social security disability benefits. There are currently 61 co-sponsors in the Senate and 237 co-sponsors in the House.

continued on page 2



I AM ALS advocates meet with the FDA in advance of the release of an updated ALS clinical trials document.

4. Get your colleagues on board. In 2020 we set out to build the Congressional House ALS Caucus to 150 members and grow the Congressional Senate ALS Caucus to 25 members.

Congressional Bills In Action

- **The Access to Disability Benefits:** The ALS Disability Insurance Access Acts of 2019 ([H.R. 1407](#) and [S. 578](#)) now has 237 House co-sponsors and 61 Senate co-sponsors. This bill amends the Social Security Act to eliminate the five-month waiting period for disability insurance benefits for ALS patients. It will give financial relief for patients and their families in a disease where the patient typically does not live longer than two to five years.
- **Access to Veteran Services:** The Justice for ALS Veterans Act of 2019 ([H.R. 4748](#) and [S.3091](#)) continues payments to widows/widowers of veterans who have passed from ALS. It is estimated that the yearly healthcare costs for ALS range from 16k to 200k in addition to a potential loss in a spouse's income who needs to quit their job to become the primary caregiver for the patient.

- **Access to Needed Respiratory Therapy:** The Safeguarding Medicare Access to Respiratory Therapy Act of 2019 ([H.R. 4945](#)) would put a five-year delay on the Centers for Medicare and Medicaid (CMS) from taking ventilation devices out to bid from the Medicare competitive bidding program for home medical equipment. It will also create a technical expert panel to assist the Department of Health & Human Services (HHS) in developing a comprehensive Medicare coverage policy for ventilator products used at home.
- **Access to Promising Therapies:** The current treatment development pipeline for diseases like ALS is very promising. I AM ALS continues to work with Congressional champions to enact changes to our clinical trial and health care systems which currently do not meet the needs of those living with ALS and other rapidly progressing fatal diseases. I AM ALS supports the implementation of effective pathways for access to promising therapies that have been proven safe. We stand ready to work with Congress.



ALS patients Steve Gleason, Brian Wallach and Dan Tate meet with Senator Coons, Senator McSally, Senator Murkowski and Senator Braun in advance of Steve Gleason's Congressional Gold Medal Ceremony.