



ALS Congressional Caucus Update

2020 Fourth Quarter | Issue 2

"Hope is not made real in one day. It takes determination day after day after day. But I would posit that there is no better moment in life than when that investment comes to fruition and the arc bends just a bit towards that brighter future for all."

-- I AM ALS Co-Founder [Brian Wallach](#)

Hi ALS Champion

Welcome to the second edition of the ALS Congressional Caucus Update! Our end goal is for ALS to take a long walk off a short pier. We are grateful for your commitment and hope this update provides opportunities to show your support as well as gives you a glimpse of what the passionate ALS community is doing to advocate for an end to ALS.

Poll Question

Have you or your legislator been impacted by ALS?

IF YES, CLICK
HERE

Take Action

Schedule. The. Vote. Now.

With the end of the year fast approaching, ALS advocates across the country are raising their voices in support of [H.R.1407/S.578](#), the ALS Disability Insurance Access Act of 2019. Unity resounds more than ever with sweeping congressional support -- we know that many of you stood up for this bill becoming law. We ask you to help make this real. Schedule. The. Vote. Now.

[Click here to share the tweet below:](#)

● I'm proud to be a champion for ALS advocates. A unified Congress is ready to change lives. @SpeakerPelosi @senatemajldr @SenSchumer @GOPLeader it's time to bring H.R.1407/S.578 to the floor for a vote.

Congressional Updates

H.R.1407/S.578

The ALS Disability Insurance Access Act of 2019 ([H.R.1407](#) and [S.578](#)) now has 300 House cosponsors and 67 Senate cosponsors. This bill amends the Social Security Act to eliminate the five-month waiting period for disability insurance benefits for ALS patients. With nearly 370 cosponsors, I AM ALS is grateful to each Member for their support and stands ready to make this bill a reality for millions of Americans living with ALS. To become a cosponsor of S.4867 contact Sen. Chris Coons' office (Corey_Linehan@coons.senate.gov) or Sen. Lisa Murkowski's office (angela_ramponi@murkowski.senate.gov)

H.R.7071

The bill has been reintroduced as [H.R.8662](#), with a companion bill in the Senate, [S.4867](#). The Accelerating Access to Critical Therapies for ALS (ACT for ALS) Act is a bill to speed up patient access to promising

therapies. The ACT for ALS bill increases the opportunity for patients to access investigational therapies outside of clinical trials, particularly for those who may not live long enough to benefit from a drug eventually being approved. It also creates an HHS Collaborative for Neurodegenerative Diseases jointly led by the Food and Drug Administration (FDA) and the National Institutes of Health (NIH) to advance the development of and streamline review and approval of effective therapies to treat neurodegenerative diseases. We hope you'll consider cosponsoring H.R.8662 and S.4867 now! To become a cosponsor please contact Rep. Jeff Fortenberry's office (reyn.archer@house.gov) or Rep. Mike Quigley's office (Allison.jarus@mail.house.gov).

FY 2021 Appropriations

I AM ALS aimed to build on the achievements included in last year's FY2020 Appropriations bill and asked Congress to fund the United States Department of Defense (DOD) ALS Research Program (ASLRP) at the level of \$40 million, provide an increase of no less than \$20 million for ALS research at the National Institutes of Health (NIH), and fund the Centers for Disease Control and Prevention (CDC) National ALS Registry at the level of \$10 million. We stand ready to work with both chambers to continue to support ALS research through federal appropriations.

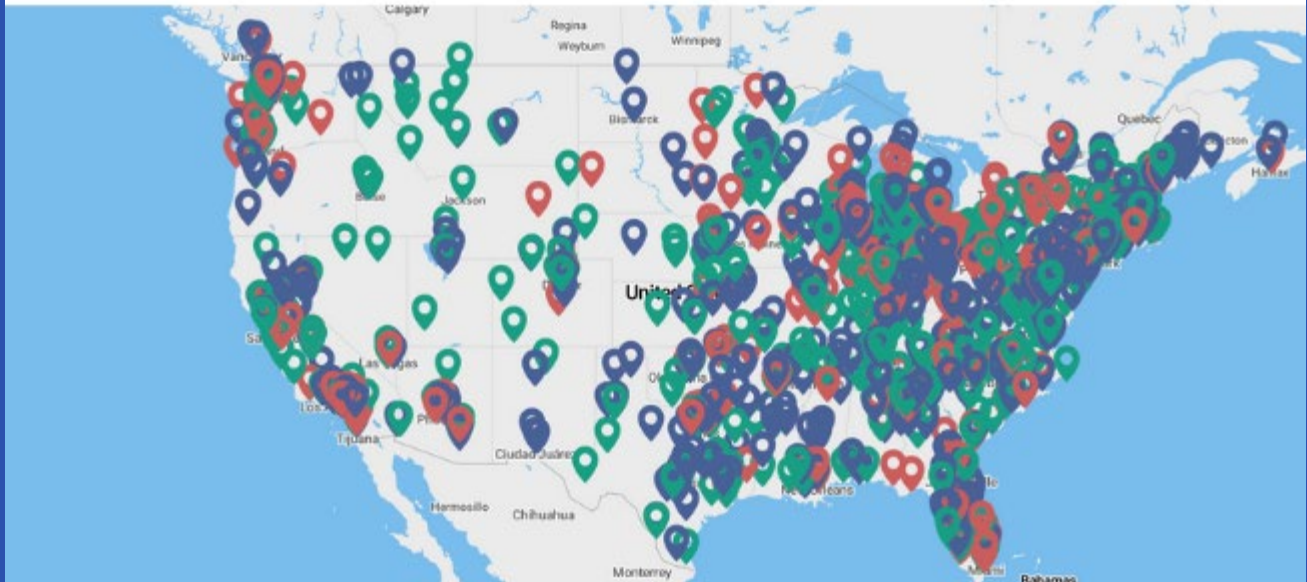
The ALS Community

The ALS community is made up of our family, friends, loved ones and neighbors nationwide.

Below is a map that shows the thousands of Americans living and impacted by ALS representing every congressional district. It will take all of us to overcome this disease and we are united in our common goal to #EndALS.

Every Community Map

■ I am living with ALS ■ I am or was an ALS caregiver ■ Someone we've lost to ALS



The House and Senate ALS Caucus - Two Chambers, One Mission.

The House and the Senate ALS Caucus's mission is to bring together members of Congress from both sides of the aisle to share experiences, exchange ideas, and work collaboratively to find a cure for ALS. By raising awareness about the challenges faced by ALS patients and their families, thinking creatively about policy solutions to reduce the negative impacts of ALS, and investing in groundbreaking research, we will find a cure. Together.



I AM ALS is a patient-led community that provides critical support and resources to patients, caregivers and loved ones. It empowers advocates to raise mainstream awareness and lead the revolution against ALS in driving the development of cures.

Learn more at iamals.org.

I AM ALS



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[I AM ALS website](https://iamals.org)

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