



# ALS Congressional Caucus Update

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"Hope is the embrace of the unknown, and acting, even though you don't know who your actions will benefit, or when they will come to fruition."

-- I AM ALS Co-Founder Brian Wallach

## Welcome

Welcome to the third edition of the ALS Congressional Caucus Update! I AM ALS puts this together to provide important updates on relevant legislation and efforts by ALS advocates to end ALS and create a future free of all neurodegenerative diseases.

We began 2021 with ALS advocates across the country celebrating the passage of [S.578](#), the ALS Disability Insurance Access Act of 2019. The new bill eliminated the five-month waiting period for disability benefits for those living with ALS. We are thankful to policymakers for prioritizing this

## Be the ALS Champion the Community Needs

When ACT for ALS is reintroduced we will work like mad to quickly gain the support we need to pass this bill. Can you commit to working to get two of your colleagues on board as co-sponsors for ACT for ALS when it is reintroduced?

[FIND OUT  
MORE ABOUT  
ACT FOR ALS](#)

meaningful legislation in the midst of the Covid-19 pandemic and for uniting to pass this bipartisan bill and give financial dignity to people living with ALS.

As 2021 ramps up, we are working with ALS advocates across the country to submit letters to the editor (LTE) or op-eds with local publications in support of ending ALS. If your office would be interested in submitting an op-ed as a congressional champion or alongside a constituent about the work being done toward driving cures for ALS, please reach out to [media@iamals.org](mailto:media@iamals.org).

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

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

Thank you to our ALS Caucus  
Co-Chairs!

[Senator Chris Coons \(D-DE\)](#)

[Senator Mike Braun \(R-IN\)](#)

[Congressman Jason Crow \(D-CO\)](#)

[Congressman Brian Fitzpatrick \(R-PA\)](#)

[Congresswoman Terri Sewell \(D-AL\)](#)

[Congressman Ken Calvert \(R-CA\)](#)

## I AM ALS 2021 Policy Priorities

### **1. Pass the ACT for ALS legislation to increase access to critical treatments for ALS patients now**

Accelerating Access to Critical Therapies (ACT) for ALS increases access to investigational therapies (those still being studied in clinical trials) by providing a grant program to fund expanded access for therapies being developed by small biopharmaceutical companies. Additionally, it creates a public-private partnership with National Institutes of Health (NIH) and the Food and Drug Administration (FDA) to speed the development and approval of therapies for ALS and other neurodegenerative diseases and creates an FDA grant program to make progress on neurodegenerative disease prevention, diagnosis and treatments and cures. These critical steps are necessary to deliver improved outcomes for people living with ALS today. I AM ALS looks forward to the introduction of this bill in the coming weeks.

### **2. Reach a goal of a \$100M increase in federal ALS research funding over three years**

At our founding, we set the bold goal to increase federal funding for ALS research by \$100M in our first three years to counteract the years of underfunding. The ALS community rallied to achieve this ambitious mark, driving up ALS research budgets by a total of more than \$80M in our first two years. We will double down on this progress by working with agency

leadership and Congressional champions to continue to increase budgets for ALS research at the NIH and the Department of Defense ALS Research Program.

### **3. Continue to support and drive forward legislation such as the Promising Pathway Act to create a patient-centric drug development and regulatory system**

For those living with ALS today, nothing is more essential than ensuring access to safe and promising therapies as soon as possible. We stand by [these principles](#) to quicken patients' access to therapies as steadfastly today as when we first published them. We will continue to work with the FDA and Congressional champions to create a drug approval system that reflects the urgency felt by those living with ALS and other diseases.

### **4. Grow the Congressional ALS Caucus and launch similar regional advocacy teams to make an impact at both the federal and state level**

By growing the ALS Caucus and the presence of ALS champions in Congress, as well as on regional teams across the country, I AM ALS will continue growing a community of champions who can deliver meaningful change at the state and federal policy levels.

### **5. Drive policy changes that make a difference in the lives of families impacted by ALS**

We equip our extensive network of fierce advocates with the tools they need to support legislative priorities for individuals impacted by ALS. These include: speeding regulatory approval and increasing access to investigational therapies; providing patient support; addressing issues related to ALS gene carriers and hereditary ALS; revamping policies to support devices and technology; and improving care and resources for veterans.



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 awareness and lead the revolution against ALS in driving the development of cures. Learn more at [iamals.org](http://iamals.org).

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I AM ALS



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