

September 22, 2026

Dear Majority Leader Thune, Minority Leader Schumer, Chairman Cassidy, and Ranking Member Sanders,

We are a community of people living with and impacted by ALS across the country; Americans who are fighting for our lives. We urge the Senate to pass the ACT for ALS Reauthorization Act (H.R.8205) immediately, before leaving for the October recess, and send it to the President for signature before the law's lifesaving programs's authorization expires on October 1st, 2026.

If Congress allows that deadline to lapse in just days, it risks interrupting the only path many Americans with ALS have to investigational treatments that give them a chance at slowing the disease, and jeopardizes a system of data, learning, and research needed to develop the next generation of drugs. Expanded Access Programs (EAPs) under ACT for ALS provide investigational treatments to people who otherwise have no options, while generating vital data that have been used to evaluate ALS drugs and other neurodegenerative disease treatments. A survey of clinical trial sites showed that because of ACT for ALS, 25% of all sites were able to offer EAPs to patients for the very first time, and 50% of clinical trial sites reported that funding helped increase their research capacity. The headline here is that the U.S. has significantly ramped up our research capacity and offerings because of this law.

ALS progresses quickly, with a median survival of just two to five years. ACT for ALS-funded EAPs are often the only opportunity people have to try investigational treatments. The programs were designed to also contribute data to ongoing research so that we're simultaneously learning. Plus, ACT for ALS supports a system of research efforts, a public-private partnership, and the single biggest bloodbank of ALS biomarker and patient samples benefiting researchers - not just for ALS, but across neurodegenerative disease science. By funding aggressive, targeted research into ALS through this Act, you are effectively funding the foundational science needed to develop therapies, diagnostics, prevention tools, and cures for the millions of Americans suffering from neurodegenerative diseases as a category - FTD, Alzheimer's, MS, Parkinson's, Huntington's, and beyond.

There is no other country in the world that is doing this. This is American leadership that cannot and has not been matched anywhere else in the globe.

If the Senate does not act this week or next, the earliest the bill could realistically be enacted is mid-November. A 60-day delay may be manageable on a legislative calendar, but it is not manageable for a person with ALS. In that time, a person living with ALS can lose the ability to walk, use their arms, speak, or breathe. For people confronting a relentlessly progressive and fatal disease, this is not an abstract legislative deadline. The urgency of the disease demands action. Every day matters.

The Senate and House have already unanimously passed bipartisan ACT for ALS reauthorization bills. The remaining differences are technical and minor; neither version warrants delaying action while patients' access to promising therapies is put at risk. The Senate's passage of the House bill this week or next is the only viable path to signing the ACT for ALS Reauthorization Act into law by October 1st.

Congress created ACT for ALS because there were no viable options for people with ALS. Letting it expire doesn't preserve caution; it takes away the only access some have left.

A lapse in ACT for ALS authorities could place critical ALS research and Expanded Access Programs in jeopardy, disrupting access to investigational treatments and research they support. For people with ALS, that risk is quite literally a matter of life and death.

Congress has consistently demonstrated overwhelming bipartisan support for ACT for ALS. Now it must finish the job. We respectfully urge the Senate to pass ACT for ALS reauthorization before the October recess so that the bill can reach the President's desk before October 1st.

There can be no interruption in access, no loss of momentum, and no uncertainty of your support for people living with ALS. The Senate must act now.

With hope and urgency,

Brian Wallach, Co-founder, I AM ALS and person living with ALS

Sandra Abrevaya, Co-founder, I AM ALS and ALS caregiver

Steve Gleason, Co-founder, Team Gleason Foundation and person living with ALS

Andrea Goodman, CEO, I AM ALS

