July 17, 2026

Members of the U.S. House of Representatives
Washington, DC 20515

Re: Please Vote Yes on the ACT for ALS Reauthorization Act (H.R. 8205)

Dear Representative:

The undersigned leading organizations serving individuals affected by amyotrophic lateral sclerosis (ALS) urge you to vote yes on the Accelerating Access to Critical Therapies for ALS Reauthorization Act of 2026 (ACT for ALS Reauthorization Act) (H.R. 8205) when it comes before the House of Representatives for a vote.

ALS is an unrelenting rare neurodegenerative disease that attacks the motor neurons, leading to progressive, often rapid, muscle weakness and eventually paralysis and respiratory failure. Despite over a century of medical research, there is still no cure for ALS. The disease remains a severely under-researched disease, with very few FDA-approved treatments, and little has demonstrably changed in the rate of disease progression for those living with ALS. Veterans are also up to two times more likely to develop ALS than the general population, further underscoring the urgent need for continued investment in ALS research, care, and treatment development.

This is why the ACT for ALS, enacted in 2021, was so critical to those living with ALS. The program expanded access to promising investigational therapies for individuals living with ALS who otherwise had no remaining treatment options, while also strengthening national ALS research infrastructure. Clinics across the country, including the first clinics in Iowa and Idaho, are now newly able to participate in ALS research. ACT for ALS also supported the development of several public-private partnerships focused on accelerating ALS and other rare neurodegenerative disease drug development. The Food and Drug Administration has issued over $20 million in grants for ALS and rare neurodegenerative disease drug development and has coalesced around a regulatory action plan to innovate ALS regulatory approaches.

This positive momentum will stall unless Congress passes the ACT for ALS Reauthorization Act prior to October 1st. This legislation renews these vital programs while making small, targeted updates to the ACT for ALS initiatives. The Energy and Commerce Committee has acted swiftly to report this reauthorization to the full House, unanimously completing their efforts in just over one month following the bill's introduction.

It is now time for the House of Representatives to act quickly and pass the ACT for ALS Reauthorization Act. Allowing these programs to lapse would disrupt important research and treatment-development efforts at a time when the ALS community urgently needs Congress to build upon the progress already underway. For people living with ALS and their loved ones, every moment matters, and the community cannot afford any delays in the continuation of these critical, life-changing initiatives.

We respectfully urge you to vote yes on H.R. 8205.

Sincerely,

ALS Association
ALS Network
ALS United
I AM ALS
Les Turner
Muscular Dystrophy Association