ALS United Applauds Passage of ACT for ALS Reauthorization Legislation

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WASHINGTON, D.C. — ALS United applauds the U.S. House of Representatives for passing the ACT for ALS Reauthorization Act of 2026 (H.R. 8205), an important step toward protecting federal programs that expand access to investigational therapies and strengthen the national ALS research infrastructure.

The vote also reflects the sustained engagement of people living with ALS, families, caregivers, clinicians, researchers, and advocates across the country who shared their experiences and urged Congress to act with the urgency this disease demands.

“House passage is a major step toward ensuring that the progress made possible by ACT for ALS can continue,” said Jerry Dawson, President and CEO of ALS United. “We are grateful to the bipartisan leaders who moved this legislation forward and to advocates across the ALS community who helped make this vote possible. We’ve spent the past several months bringing people living with ALS directly into congressional offices, from Hill Days to meetings with committee staff, and this vote reflects that work. Now, the Senate needs to move with the same urgency. People living with ALS don’t have time to wait.”

Since its enactment in 2021, ACT for ALS has helped build shared data platforms, natural history studies, biomarker efforts, and drug-development tools needed to move promising therapies forward faster and with greater coordination. The law has also supported NIH-funded Expanded Access Programs that allow people living with ALS who cannot enroll in traditional clinical trials to pursue investigational therapies while contributing evidence that can inform future research and regulatory decisions.

Without reauthorization, Expanded Access Programs serving hundreds of people living with ALS will begin winding down, support for the ALL ALS natural history initiative will be jeopardized, and the shared data and research infrastructure accelerating ALS therapy development will face disruption.

A Senate companion introduced by Senators Lisa Murkowski and Chris Coons (S. 4472) was reported out of the Senate Health, Education, Labor, and Pensions Committee by unanimous voice vote on June 17 and awaits floor action.

House passage is a major milestone, but the work is not finished. The current authorization expires on September 30, 2026. ALS United urges the Senate to act swiftly and send ACT for ALS

reauthorization to the President’s desk before the deadline so patients do not lose access, research sites can sustain momentum, and the ALS field can continue building the coordinated infrastructure needed to accelerate the development of effective treatments.

ALS United is grateful to Representatives Mike Quigley and Ken Calvert for their leadership, to the bipartisan members of the House who supported passage, and to advocates throughout the ALS community who helped bring reauthorization closer to the finish line.

Together, we end ALS!®

About ALS United

ALS United is a national partnership of independent nonprofit organizations united in serving people living with ALS. Its member organizations provide personalized care and support in communities across the country while working together to advance research, strengthen clinical partnerships, and advocate for policies that improve the lives of people affected by ALS.

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