ALS United Celebrates Final Congressional Passage of ACT for ALS Reauthorization

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WASHINGTON, D.C. — ALS United today celebrated the Senate's passage of the ACT for ALS Reauthorization Act of 2026, completing congressional action on the legislation and sending it to the President's desk for signature.

The bipartisan legislation will reauthorize ACT for ALS through fiscal year 2031, continuing federal efforts to accelerate the development of new therapies and expand access to investigational treatments for people living with ALS. It will preserve the foundation established when ACT for ALS was first enacted in 2021 and allow these programs to continue supporting the ALS community into the next decade.

"Today is an important moment for the ALS community, and it belongs first and foremost to the people who made it possible," said Jerry Dawson, President and CEO of ALS United. "People living with ALS, families, caregivers, researchers, clinicians, advocates, and our member organizations have been educating lawmakers, sharing their experiences, and making sure Congress understood why this work could not stop. We are incredibly grateful to everyone who helped carry ACT for ALS across the finish line."

ALS United member organizations played a central role throughout the reauthorization effort. In May, ALS United members brought more than 50 advocates to Capitol Hill for Hill Day, others met with lawmakers in their home districts. ALS United also organized a congressional briefing and engaged with House and Senate committees, while advocates and coalition partners maintained grassroots outreach throughout the legislative process.

"Reauthorization reflects years of work across the ALS community," Dawson said. "Our members showed up—in Washington, in their communities, and in conversations with policymakers—to make sure the experience of people living with ALS was part of this process. We are proud of what this community accomplished together."

First enacted in 2021, ACT for ALS was created to address two critical challenges facing people living with ALS: accelerating the development of new therapies and expanding access to investigational treatments for people who are unable to participate in traditional clinical trials. The law has also supported shared research infrastructure, natural history and biomarker efforts, data resources, and evidence-generating expanded access programs that help connect patients, researchers, clinicians, government, and industry.

The Senate's action today approves H.R. 8205, which the House passed in July. The Senate passed its own version of the legislation in August. Today's action completes congressional consideration of the reauthorization and sends the bill to the President for signature.

"We are grateful to the bipartisan leaders who championed this legislation and helped carry it through Congress," Dawson said. "Senators Lisa Murkowski and Chris Coons and Representatives Mike Quigley and Ken Calvert have been tireless champions for the ALS community, and we deeply appreciate their leadership throughout this process. We also thank the many members of Congress and congressional staff who worked across the aisle to get this legislation to the President's desk."

ALS United will continue working with its member organizations, coalition partners, researchers, clinicians, and people living with ALS and their families to help sustain these programs, support new grant and research opportunities, and build on the progress achieved under ACT for ALS.

About ALS United

ALS United is a national partnership of 15 independent nonprofit organizations united in serving people living with ALS. Together, our member organizations serve approximately one in three people impacted by ALS in the United States, providing 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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