Congress Must Finish the Job on ACT for ALS Reauthorization Before Recess, Says ALS United

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WASHINGTON, D.C. — ALS United today called on congressional leaders to resolve the remaining differences between the House- and Senate-passed ACT for ALS Reauthorization and send final legislation to the President's desk before the House departs for fall recess at the end of the week.

Both chambers passed their own versions of the reauthorization over the summer, and Congress must now resolve the remaining differences and agree on a final bill. The House passed its version, H.R. 8205, on July 22, led by Representatives Mike Quigley (D-IL) and Ken Calvert (R-CA). The Senate passed its version, S. 4472, led by Senators Lisa Murkowski (R-AK) and Chris Coons (D-DE), the week of August 3. Without reauthorization, ACT for ALS programs face expiration, threatening the future of expanded access, research opportunities, and the shared infrastructure that is helping scientists, clinicians, and federal agencies and industry work more effectively together.

"We're thankful that members of both the House and Senate worked over the summer to pass their versions of this bill," said Jerry Dawson, President and CEO of ALS United. "These bills aren't far apart, and we believe the House and Senate can reconcile them in a way that works for people living with ALS, researchers, and everyone working to get this right. People living with ALS don't have months to wait. Congress needs to finish this work and get it done before they leave town."

ALS is a rapidly progressive and fatal neurodegenerative disease that affects more than 35,000 Americans. Most people living with ALS still have limited treatment options, and many are excluded from clinical trials because of disease progression, geography, restrictive eligibility criteria, or other barriers that make participation impossible.

The programs authorized under ACT for ALS were created with them in mind. By supporting Expanded Access Programs, the law has opened investigational treatment pathways for people who may otherwise have no options. At the same time, it has helped build shared research tools, data systems, biomarker efforts, and natural history studies that make ALS research more coordinated, efficient, and responsive to real-world patient needs.

"Every week of delay is a week that people with ALS don't get back," Dawson said. "Congress has the opportunity to finish this work now and complete reauthorization before the House leaves for recess."

ALS United is urging supporters to contact their members of Congress this week and ask congressional leaders to complete ACT for ALS reauthorization before the fall recess begins.

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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