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ALS United Applauds Senate Introduction of ACT for ALS Reauthorization Legislation

Bipartisan bill from Senators Murkowski and Coons would extend landmark federal programs supporting ALS research and expanded access to treatments.

ALS United Logo

WASHINGTON, DC, UNITED STATES, May 1, 2026 /EINPresswire.com/ -- ALS United today applauded the Senate introduction of the Accelerating Access to Critical Therapies (ACT) for ALS Reauthorization Act by Senator Lisa Murkowski (R-AK) and Senator Chris Coons (D-DE). The bipartisan legislation would extend a landmark federal program that has helped strengthen ALS research infrastructure and expand access to investigational therapies for people living with ALS.

First enacted in 2021, ACT for ALS was designed to help address two urgent challenges facing the ALS community: the need to accelerate therapy development and the need to reach patients who are often unable to participate in traditional clinical trials. Since then, the law has supported coordinated natural history and biomarker research, open data resources, and NIH-funded Expanded Access Programs that allow patients to pursue investigational therapies while contributing to the evidence base needed to move ALS science forward.

“ACT for ALS has helped turn urgency into action by building the research infrastructure, data systems, and expanded access pathways needed to move promising therapies closer to people living with ALS,” said Jerry Dawson, President and CEO of ALS United. “This law is making a real difference. The ALL ALS natural history study is now enrolling participants across dozens of sites, and NIH-funded expanded access programs are connecting patients to investigational treatments while generating evidence that can help inform the next generation of ALS therapies. We are deeply grateful to Senators Murkowski and Coons for their bipartisan leadership and for recognizing that this work cannot afford to stop.”

ALS is a rapidly progressive and fatal neurodegenerative disease that affects more than 30,000 Americans. Most people living with ALS still have limited treatment options, and many patients 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 those patients 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 can make ALS research more coordinated, efficient, and responsive to real-world patient needs.
The Senate introduction marks an important step toward ensuring these programs can continue beyond the current authorization period. Without congressional action, ACT for ALS programs will begin winding down, threatening progress in expanded access, disrupting ongoing research efforts, and weakening the shared infrastructure that is helping scientists, clinicians, federal agencies, and industry work more effectively together.

ALS United urges Congress to move swiftly to pass the ACT for ALS Reauthorization Act and provide the stability needed to sustain these critical programs for people living with ALS and the researchers working to end this disease.

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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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