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ALS United Applauds Introduction of ACT for ALS Reauthorization Legislation

Bipartisan Legislation Would Reauthorize a Vital Federal Initiative That Has Helped Accelerate ALS Research

ALS United Logo

WASHINGTON, DC, UNITED STATES, April 8, 2026 /EINPresswire.com/ -- ALS United today applauded the introduction of the Accelerating Access to Critical Therapies (ACT) for ALS Reauthorization Act by Rep. Ken Calvert (R-CA) and Rep. Mike Quigley (D-IL). This bipartisan legislation would reauthorize a vital federal initiative that has helped accelerate ALS research and expand access to investigational therapies for people living with the disease.

Since its enactment in 2021, ACT for ALS has strengthened the national ALS research infrastructure and created additional options for patients who cannot participate in traditional clinical trials. The law has supported open data resources, natural history and biomarker research, and evidence-generating Expanded Access Programs that are helping researchers and patients move promising therapies forward more quickly and with greater coordination.

"ACT for ALS gave the ALS community something it has never had before. A real infrastructure for accelerating research and getting investigational therapies to people who can't wait," said Jerry Dawson, President and CEO of ALS United. "The ALL ALS natural history study now has 1,448 participants enrolled across 34 active sites. And through the expanded access programs this law created, 46 clinic sites are connecting people living with ALS to treatments they could not otherwise reach. We are grateful to Representatives Calvert and Quigley for their leadership in moving this reauthorization forward."

ALS is a rapidly progressive, fatal neurodegenerative disease that affects more than 30,000 Americans. For most people living with ALS, treatment options remain limited, and many are unable to participate in clinical trials because of disease progression, geography, or restrictive eligibility criteria.
ACT for ALS was designed to address those realities on two fronts. First, it has helped build the

shared research infrastructure needed to speed therapy development, including data platforms, common tools, and coordinated biomarker and natural history efforts. Second, it has supported NIH-funded Expanded Access Programs that allow people with ALS to pursue investigational therapies outside the traditional trial system while contributing to the evidence base that can inform future development and regulatory decision-making.

Without reauthorization, these programs will begin winding down. That would disrupt key research efforts, weaken the shared infrastructure now supporting ALS drug development, and narrow access to investigational options for people living with this disease.

"The September deadline is not abstract," Mr. Dawson added. "Without reauthorization, expanded access programs wind down, the ALL ALS natural history effort loses support, and the shared data infrastructure that is speeding therapy development goes dark. Congress needs to act now so this momentum doesn't stop."

ALS United urges Congress to move quickly to reauthorize ACT for ALS and provide the stability needed to sustain these critical programs.

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