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ALS United Statement on GAO Report Evaluating the Accelerating Access to Critical Therapies for ALS Act

WASHINGTON, DC, UNITED STATES, February 6, 2026 /EINPresswire.com/ -- The Government Accountability Office released a report evaluating the implementation of the Accelerating Access to Critical Therapies for ALS (ACT for ALS) Act on February 4, 2026. The report reflects strong early progress and reinforces what the ALS community has seen firsthand—ACT for ALS is expanding access to investigational therapies while building the research infrastructure needed to accelerate the next generation of treatments.

ALS United Logo

ACT for ALS was designed to confront one of the hardest realities of this disease: people with ALS often do not have the time to wait for traditional development timelines. The law helps eligible individuals pursue access to investigational therapies through an expanded access pathway, while also encouraging learning from patient experience to help inform future research and policy decisions.

In addition to expanded access, ACT for ALS has advanced critical public-private partnerships that accelerate research, data sharing, and coordination across the ALS ecosystem, including the creation of the Access for All in ALS (ALL ALS) initiative. Together, these efforts are building a nationwide research infrastructure, improving clinical trial readiness, and generating real-world evidence from patient experience to inform future research and regulatory decisions, ensuring the law delivers both immediate access and long-term progress.

Among the report's key findings:

Funding and implementation. Federal partners awarded about $276 million from fiscal years 2022 through 2025 to implement ACT for ALS, supporting expanded access to investigational drugs, a rare neurodegenerative disease public-private partnership, and additional research and clinical development efforts.

Expanded access nationwide. Approximately 750 people with ALS are expected to receive access to investigational drugs through five National Institutes of Health (NIH) expanded access grants, supported by 46 clinic sites prepared to enroll participants across 25 states, Washington, D.C., and Puerto Rico, alongside a remote option that can reach participants nationwide.

Reach and data backbone. ACT for ALS investments are also powering large-scale, inclusive research. As of November 2025, 1,123 participants were enrolled in the two Access for All in ALS Consortium natural history studies at 33 research sites in 25 states, Washington, D.C., and Puerto Rico. The ALS Knowledge Portal, publicly available since August 2025, is centralizing high-quality ALS datasets for researchers, with 16 datasets listed as of September 2025.

“For people living with ALS, time is everything,” said Jerry Dawson, President and CEO of ALS United. “This GAO report underscores that ACT for ALS is doing what Congress intended—opening doors to investigational options for families who can’t afford to wait, and creating a more coordinated research ecosystem that will speed the path to better, more effective therapies.”

GAO noted that launching a first-of-its-kind program takes real coordination, including funding and operational timelines that can shape how quickly sites move from award to enrollment. NIH and FDA have already taken steps to keep implementation moving, and the report underscores that many of the most consequential research components supported by the law are now underway—meaning ACT for ALS’ impact will continue to grow.

ALS United urges Congress to reauthorize ACT for ALS and provide stable, predictable funding so patients do not lose access to investigational therapies, research sites can sustain momentum, and the ALS field can continue building the shared data resources needed to drive breakthroughs. We look forward to working with bipartisan champions, federal partners, and the broader ALS community to strengthen and extend this law’s impact.

ALS United remains committed to advancing policies that expand access to care, accelerate the development of effective treatments, and improve quality of life for everyone affected by ALS.

Together, we end ALS!®

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