April 14, 2026

The Honorable Morgan Griffith
Chairman, Subcommittee on Health
Committee on Energy and Commerce
U.S. House of Representatives
Washington, DC 20515

The Honorable Diana DeGette
Ranking Member, Subcommittee on Health
Committee on Energy and Commerce
U.S. House of Representatives
Washington, DC 20515

Dear Chairman Griffith and Ranking Member DeGette:

On behalf of ALS United and the people living with ALS and families we serve nationwide, we submit this statement for the record for the Subcommittee's April 15, 2026, legislative hearing to express our strong support for the Accelerating Access to Critical Therapies for ALS Reauthorization Act of 2026 (H.R. 8205).

ALS United is the largest provider of local, community-based ALS care services in the United States—a federation of 15 independent nonprofits with dedicated staff working alongside patients and families in communities across the country every single day. Through direct services, 92+ multidisciplinary care center partnerships, and wraparound support, our member organizations collectively serve more than half of all people living with ALS nationwide. Because we are embedded in communities—not just connected to them—we bring a grounded, real-time perspective on what ACT for ALS is delivering.

ALS is a rapidly progressive, fatal neurodegenerative disease, and for most people living with ALS, treatment options remain limited. Families do not have the luxury of waiting years for the traditional drug development timeline. Congress recognized that reality when it enacted ACT for ALS in 2021. The law established a practical, patient-centered approach to accelerate progress on two fronts at once: building the shared research infrastructure needed to move promising therapies forward faster, and expanding access to investigational therapies for people who cannot participate in traditional clinical trials.

That approach is already producing meaningful results. ACT for ALS has helped strengthen the national ALS research infrastructure through open data resources, natural history and biomarker research, and coordinated public-private efforts that are improving how the field develops and evaluates therapies. Separately, it has supported evidence-generating Expanded Access Programs that connect people living with ALS to investigational therapies while contributing to the evidence base that can inform future development and regulatory decision-making. The law's impact can already be seen across both areas—from the ALL ALS natural history study, which has enrolled 1,448 participants across 34 active sites, to the Expanded Access Programs now operating through 46 clinic sites.

ACT for ALS is helping build the shared data backbone, research coordination, and expanded access pathways that the ALS community has long needed. It is making ALS research more connected and more representative of the real-world patient population, including people who are often excluded from traditional clinical trials because of disease progression, geography, or medical complexity.

That is why reauthorization is so important. Without congressional action before September 2026, key ACT for ALS programs and authorities will begin to wind down. Expanded access efforts will lose support, the ALL ALS natural history initiative will be disrupted, and the shared data and collaboration infrastructure that is accelerating therapy development will be weakened at precisely the moment it is beginning to demonstrate its value. Congress should not allow successful programs that are already helping patients and researchers to lapse.

The Accelerating Access to Critical Therapies for ALS Reauthorization Act of 2026 extends these efforts and preserves the momentum the ALS community has worked so hard to build. Just as importantly, the bill also includes targeted improvements based on real-world implementation that would strengthen the program and help ensure it continues delivering meaningful value.

In particular, the bill would clarify eligibility for Phase 2/3 and planned Phase 3 trials, helping ensure that promising therapies are not excluded by narrow interpretations of the program. It would require closer review of clinical trial status when certain expanded access program grants come up for renewal, which would improve accountability and help ensure federal support remains aligned with the strongest scientific opportunities and patient benefit. It would require updated FDA planning and reporting, which would provide greater transparency into implementation progress, resource needs, and next steps for advancing ALS and other rare neurodegenerative disease work. It would also require additional GAO follow-up, helping Congress continue to evaluate how the law is being carried out and whether reauthorization is producing the intended results.

Taken together, these changes make a strong law stronger. They preserve access, reduce ambiguity, reinforce accountability, and help ensure that ACT for ALS continues evolving in ways that reflect both scientific realities and the urgent needs of people living with this disease.

ALS United appreciates the bipartisan leadership of Representatives Quigley and Calvert and the Subcommittee's attention to this important legislation. We respectfully urge the Subcommittee to advance the Accelerating Access to Critical Therapies for ALS Reauthorization Act of 2026 and help ensure that the progress ACT for ALS has already delivered is not interrupted. People living with ALS cannot afford to lose momentum in research, coordination, and access to investigational therapies.

Sincerely,

Jerry Dawson
President and CEO
ALS United