August 19, 2026

The Honorable Bill Cassidy, M.D.
Chairman
Committee on Health, Education, Labor, and Pensions
United States Senate
428 Dirksen Senate Office Building
Washington, DC 20510

The Honorable Brett Guthrie
Chairman
Committee on Energy and Commerce
U.S. House of Representatives
2125 Rayburn House Office Building
Washington, DC 20515

The Honorable Bernie Sanders
Ranking Member
Committee on Health, Education, Labor, and Pensions
United States Senate
332 Dirksen Senate Office Building
Washington, DC 20510

The Honorable Frank Pallone, Jr.
Ranking Member
Committee on Energy and Commerce
U.S. House of Representatives
2107 Rayburn House Office Building
Washington, DC 20515

Re: Comments on ACT for ALS Reauthorization

Dear Chairman Cassidy, Ranking Member Sanders, Chairman Guthrie, and Ranking Member Pallone,

We appreciate the opportunity to provide additional perspective as Congress works toward final passage of the ACT for ALS Reauthorization Act of 2026. We are deeply grateful to the Committees, the bill's sponsors, and the bipartisan champions in both chambers for their leadership and for the tremendous work that has brought this legislation to this point. The strong bipartisan support for ACT for ALS in both the House and Senate reflects the importance of these programs to people living with ALS, their families, researchers, clinicians, and the broader ALS community.

Our highest priority is enactment of a full five-year reauthorization before the current authorization expires on September 30. With a limited number of legislative days remaining when Congress returns in September and a crowded fall agenda, we strongly encourage the Committees and congressional leadership to move as quickly as possible toward enactment.

With that priority in mind, and after reviewing both versions and considering the experience of the ALS community under the original ACT for ALS, we believe the Senate-passed version provides the clearest path forward. Our preference reflects several substantive provisions in the Senate bill that we believe should be preserved, particularly the Senate's additional oversight provision and the connection between expanded access and ALS research and therapeutic development.

As Congress moves toward final passage, we respectfully encourage Congress to preserve the following priorities in the final legislation.

Preserve the full five-year reauthorization through 2031 without interruption

The final legislation should preserve the full five-year reauthorization through 2031 and ensure that the programs established under ACT for ALS continue without interruption.

These programs have become an important part of the infrastructure supporting people living with ALS, researchers, clinicians, and therapeutic developers. An interruption in authorization could create unnecessary uncertainty for ongoing expanded-access efforts, research activities, and partnerships

supported through the program. We therefore strongly support completing the legislative process and enacting the reauthorization before September 30.

Maintain strong accountability and oversight

We support the strong accountability and oversight framework reflected in both chamber-passed bills, including requirements for FDA to update its Action Plan and for GAO to conduct additional work evaluating the effectiveness of the ACT for ALS grant programs. We appreciate that both versions preserve these important mechanisms for assessing implementation and ensuring continued visibility into the program's progress.

We also support the Senate-passed provision establishing additional HHS oversight of the implementation of ACT for ALS. We believe this additional oversight can help Congress and the ALS community evaluate how effectively the program is being implemented and identify opportunities to strengthen its impact.

We also support meaningful safety reporting that provides policymakers and the ALS community with useful information without creating unnecessary administrative burdens for researchers, grant recipients, FDA, or other stakeholders. We believe the Senate-passed approach strikes an appropriate balance and encourage Congress to preserve these provisions in the final legislation.

Preserve the connection between expanded access and ALS research

We support the Senate-passed provision requiring applicants for expanded-access grants to describe how data generated through the grant will be used to support ALS research or therapeutic development.

Expanded access provides an important pathway for people living with ALS who may not have a viable opportunity to participate in a clinical trial to receive investigational therapies. At the same time, the experience and information generated through expanded-access programs can provide valuable insight for researchers and therapeutic developers.

Maintaining a clear connection between expanded access, research, and therapeutic development can help ensure that information generated through these programs contributes, where appropriate and consistent with applicable privacy and research protections, to the broader effort to understand ALS and develop new treatments. We therefore encourage Congress to preserve this Senate-passed provision in the final legislation.

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We stand ready to be helpful to the Committees, sponsors, and congressional leadership as they work toward final passage. We appreciate the bipartisan commitment that has brought ACT for ALS to this point and urge Congress to complete this important work before the September 30 expiration.

Thank you again for your leadership, partnership, and continued commitment to people living with ALS and their families. We greatly appreciate everything you have done to advance ACT for ALS and look forward to seeing this important legislation enacted.

Sincerely,
ALS Association
ALS Network
ALS United
Les Turner ALS Foundation
Team Gleason
Muscular Dystrophy Association