ALS United

Advocacy Bulletin

Quarterly advocacy news, policy updates, and action opportunities

WELCOME TO OUR

Quarterly Advocacy News

CEO's Message

Welcome to our very first newsletter — and thank you for being part of this movement. What makes ALS United different is simple: our agenda doesn't start in Washington it starts with you. Our member organizations across the country are on the ground every day alongside people living with ALS and their caregivers, and it's their experiences that shape everything we fight for on Capitol Hill. As we launch this first edition, I'm proud to share that our federal advocacy work is already in full motion, carrying real stories, real urgency, and one unified national message into the halls of Congress. This is what it looks like when local voices drive national change, and we're just getting started.

Warm regards,

Jerry Dawson
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ALS United Applauds ALS Funding Increases in 2026 Government Spending Package

ALS United recognizes the advocates across the ALS community whose sustained engagement helped secure meaningful new investments in ALS research and related programs in the fiscal year (FY) 2026 federal funding package released by Congress. By sharing their stories and pressing for urgency, advocates played a critical role in advancing progress for people living with ALS. The agreement reflects $45 million in new increases over last year for ALS-focused efforts—most notably $90 million for ACT for ALS at NIH and a new $30 million investment in ALS research through ARPA-H.

Key ALS funding outcomes in the FY26 package include:

- $90 million for ACT for ALS at NIH ($15 million increase)
- $30 million for ARPA-H ALS research (new investment)
- $145 million for NIH ALS research (level funding)
- $40 million for ALS research at the Department of Defense through CDMRP (level funding)
- $10 million for the CDC ALS Registry (level funding)

While ALS United is encouraged by the progress reflected in these final numbers, several priority requests were not fully met. ALS United had advocated for $100 million for ACT for ALS, $80 million for the DoD CDMRP ALS Research Program, $15 million for the CDC ALS Registry, and $180 million for NIH ALS research. We'll keep building on this year's gains, and look forward to collaborating with our partners for fiscal year 2027 funding priorities.

Advocacy in Action: ALS United Members Join More Than Our Stories

On February 10 and 11, several ALS United members were on the ground in D.C. for the **More Than Our Stories** conference, a hybrid gathering that pairs a day of idea-sharing with a Hill Day focused on direct advocacy. More Than Our Stories began nine years ago as an intentionally grassroots gathering created by three ALS advocates who believed people living with ALS should have the space to speak honestly about their own experiences, in their own words, not from a script. It was built as an open invitation to the entire ALS community, people living with ALS, caregivers, volunteers, researchers, clinicians, policy leaders, and anyone willing to listen and take action, grounded in the belief that authentic voices drive meaningful change.

ALS United members then focused their attention on Capitol Hill, meeting with key committee staff on the ALS Better Care Act and reauthorization of the ACT for ALS. We were proud to bring the experiences of people living with ALS and their families directly into these conversations. As we emphasized on the Hill, every decision must keep people living with ALS and their families directly into these conversations.

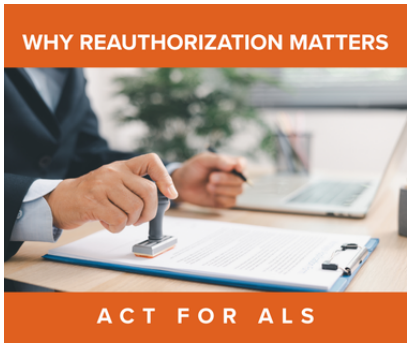
ALS Better Care Act Reintroduced with Strong Bipartisan Support

The ALS Better Care Act (S.3763/H.R.7336) is officially back in Congress, moving a step closer to strengthening Medicare support for the multidisciplinary clinic care so many people living with ALS rely on. Reintroduced on February 3 in the House by **Reps. Jan Schakowsky, Brian Fitzpatrick, Jason Crow, and Mike Quigley,** with a Senate companion from **Sens. Lisa Murkowski and Chris Coons,** the bill would establish a supplemental, facility-based Medicare payment for multidisciplinary ALS clinic visits. ALS United has been working closely with these offices and other key policymakers to help advance this approach and ensure they hear directly from the ALS community about why timely access to comprehensive clinic care matters.

This matters because multidisciplinary ALS clinics are the gold standard for care, bringing the full team together in one coordinated visit (typically every 2–3 months). The problem is that Medicare does not adequately reimburse what it takes to deliver that high-touch team-based care, which pushes clinics to operate at a loss, squeezes appointment availability, and can delay access to comprehensive care. The ALS Better Care Act is a practical Medicare fix that would add a targeted payment for multidisciplinary ALS clinic visits. As Congress moves, ALS United will continue engaging key offices and ensuring they hear directly from the ALS community about why timely access to comprehensive clinic care matters. **Contact your Member of Congress today!**

ACT for ALS Reauthorization Comes into Focus Ahead of September Deadline

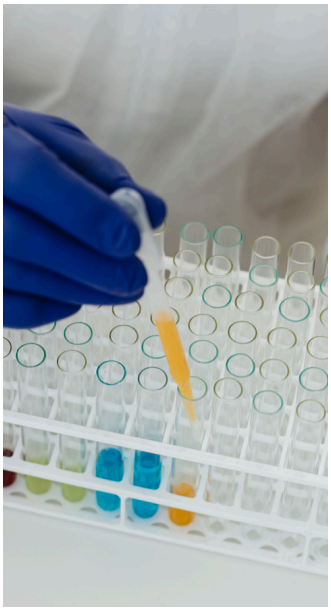
With the ACT for ALS authority set to expire in September, attention is shifting toward what reauthorization might look like, and how Congress can build on early momentum to better accelerate therapy development. Enacted in December 2021, ACT for ALS created specific tools designed to help the ALS field move faster. It authorized HHS grants to expand access to investigational therapies for people who are not eligible for clinical trials and to ensure those expanded access programs generate data that can inform research. It also established an FDA grant program to support research and development for ALS and other rare neurodegenerative diseases.



A new GAO report evaluating early implementation reinforces the progress the ALS community has seen firsthand. GAO reports that NIH and FDA awarded about $276 million from FY2022 through FY2025 to implement ACT for ALS, supporting expanded access grants and broader research infrastructure. On expanded access, GAO estimates that about 750 people with ALS are expected to receive investigational drugs through five NIH expanded access grants, supported by 46 clinic sites prepared to enroll participants across 25 states, Washington, D.C., and Puerto Rico, along with a remote option that can reach people nationwide. GAO also highlights the scale of the ALL ALS research backbone now underway, including more than 1,100 participants enrolled in natural history studies and continued development of the ALS Knowledge Portal to make datasets more accessible to researchers.

As Congress turns to reauthorization, the focus should be on protecting what's working and giving the program a stable runway so it can keep moving at the pace families need. ALS United is actively engaged in conversations among policymakers around reintroduction and will stay engaged with offices on both sides of the aisle as plans come together. At the same time, the funding bill for this year (mentioned above) would increase ACT for ALS funding at NIH to $90 million, reinforcing the importance of pairing strong resources with effective execution and a roadmap that matches what people living with ALS are up against.

Protecting Biomarker Access: ALS United Weighs In on Patent Eligibility



ALS United submitted a letter to Senate Judiciary leadership with concerns about the Patent Eligibility Restoration Act (PERA). The bill would change the rules for what kinds of discoveries can be patented, making it easier in some cases to patent diagnostic methods and claims tied closely to naturally occurring biological relationships. That matters for ALS because biomarkers and genetic insights are becoming essential to earlier diagnosis, better care decisions, and faster research progress. Those benefits depend on broad clinical access and the ability for multiple labs and research teams to validate findings and replicate results.

Our concern is that PERA, as introduced, could allow patents that functionally lock up foundational biomarker or gene–disease relationships. That can mean fewer testing options, higher costs, and slower multi-site validation and research replication. In our letter, we urged guardrails that prevent exclusive rights from attaching to basic biomarker and gene–disease relationships in ways that shift leverage away from patients and clinicians, raise testing costs, reduce clinical options, or slow the broader research ecosystem's ability to confirm and build on results.

Respiratory Access: Call for Ventilator Stories & Real-World Barriers

As recent media coverage has given renewed attention to the barriers ALS families can face in securing ventilators and respiratory supports, ALS United is collecting real-world stories about ventilator access and the day-to-day breakdowns that can put people at risk. These stories help policymakers understand what is failing in coverage and care delivery and what needs to change to keep people safe at home. A November 2025 NPR investigation helped spotlight the issue nationally, including how difficult it can be to secure the right home ventilator and how gaps in coverage and staffing can force families into impossible choices.

If you're willing to share, the most helpful details include what the patient needed, what was denied or delayed and by whom, how long the delay lasted, the out-of-pocket impact, and what happened next such as hospitalization, nursing facility placement, caregiver burnout, or missed work. De-identified stories are absolutely welcome.

Veterans with ALS Reporting Act: ALS United Expresses Support for House Bill

ALS United submitted a letter in support of the Veterans with ALS Reporting Act, a bipartisan proposal focused on strengthening accountability and building the evidence base needed to reduce risk and improve outcomes for veterans.

Veterans are twice as likely to develop ALS as the general population, yet major questions remain about why that risk exists and what can be done to reduce it for future service members.

The bill would direct the Department of Veterans Affairs, in consultation with CDC, to report to Congress on ALS among veterans, identify opportunities to develop and evaluate potential risk reduction strategies, and examine ways to improve pathways into VA-sponsored clinical trials and research. In short, it moves us from acknowledging a troubling reality to building durable systems to act.

Upcoming Events

MAY IS ALS AWARENESS MONTH

ALS United Advocacy

Washington, D.C.

May 5-6, 2026

Stay Tuned for More Details

I AM ALS Flag Event

Washington, D.C

May 7-9, 2026

Lou Gehrig Day

Major League Baseball Parks

June 2, 2026

ALS United

For more information or to get involved in advocacy efforts, please feel free to reach out to us at:

info@alsunited.org | www.alsunited.org

Your participation and support are crucial in our continued efforts to improve the lives of those affected by ALS. Whether you are a person living with ALS, a caregiver, a healthcare professional, or an ally, your voice can make a difference.

Together, we end ALS!®