# ACT for ALS Is Law

What it protects through 2031

On November 3, 2026, the ACT for ALS Reauthorization Act became **Public Law 119-138**. The law extends through fiscal year 2031 the research infrastructure and expanded access programs created when Congress first passed ACT for ALS in 2021. Advocates made that happen. People living with ALS, caregivers and families called, wrote and shared their stories until Congress acted.

## What ACT for ALS built

### *Open data and research infrastructure*

ACT for ALS created the collaboration and data backbone ALS research had long lacked: three connected platforms plus a competitive grant program.

**AMP-ALS.** A partnership with the Foundation for the NIH that aligns federal agencies, academic scientists, companies and nonprofits around shared data. Its ALS Knowledge Portal gives researchers worldwide open access to clinical datasets and adds new data and biosamples as they are generated.

**CP-RND.** A partnership between Critical Path for Rare Neurodegenerative Diseases and the FDA developing common data standards and tools so the agency can evaluate ALS treatments more efficiently, including biomarkers, modeling platforms and clinical outcome assessments.

**ALL ALS.** A natural history study with more than 1,200 participants enrolled across dozens of sites, collecting tens of thousands of samples that feed the ALS Knowledge Portal. It is the largest open natural history resource in ALS.

**Rare Disease Grant Program.** Support at NIH for research approaches, tools and infrastructure for ALS and other rare neurodegenerative diseases.

### *Evidence-generating expanded access*

Most people living with ALS never enroll in a traditional clinical trial, often because they are further along, have complex medical needs, or cannot meet eligibility criteria. ACT for ALS funds research-based Expanded Access Programs at NIH that pair access with structured learning. NIH has launched five nationwide, reaching more than 700 people living with ALS who could not otherwise receive investigational therapies. Lessons from these programs are informing what comes next, and two therapeutic candidates are advancing to Phase 3 trials.

## What reauthorization protects

Without it, the Expanded Access Programs would have wound down, ALL ALS would have lost support, and the shared data infrastructure would have been disrupted. The law instead:

- Sustains evidence generation from the full ALS population, including people usually excluded from trials.
- Keeps NIH, FDA, researchers, industry and advocates coordinated rather than siloed.
- Protects national data and biospecimen resources so discoveries build on prior contributions instead of restarting.

**The work is not finished. Authorization sets the framework. Funding is decided separately, year by year. ALS moves faster than any appropriations cycle, and the people waiting do not have time.**

**About ALS United**

ALS United is a nationwide partnership of independent nonprofit organizations serving the ALS community. Guided by our vision, Together, We End ALS®, we unite 15 member organizations to create impact through research, care and advocacy. Our network serves approximately 1 in 3 people impacted by ALS in the United States.

alsunited.org • info@alsunited.org • 9450 SW Gemini Dr, PMB 49685, Beaverton, Oregon 97008-7105