

The Honorable Susan Collins
Chair
Senate Committee on Appropriations
S-128 The Capitol
Washington, DC 20510

The Honorable Tom Cole
Chair
House Committee on Appropriations
H-307 The Capitol
Washington, DC 20515

The Honorable Patty Murray
Vice Chair
Senate Committee on Appropriations
S-128 The Capitol
Washington, DC 20510

The Honorable Rosa DeLauro
Ranking Member
House Committee on Appropriations
1039 Longworth House Office Building
Washington, DC 20515

March 18, 2025

Dear Chair Collins, Vice Chair Murray, Chairman Cole, and Ranking Member DeLauro,

On behalf of the ALS community, the undersigned organizations would like to express our appreciation for all you have provided to help improve outcomes for those living with ALS. As the Appropriations Committees begin work on the Fiscal Year 2026 (FY2026) Appropriations Bills, we respectfully request continued support for ALS programs. We ask that Congress prioritize funding for the entire ALS research ecosystem which includes fully funding the *Accelerating Access to Critical Therapies (ACT) for ALS Act*, Public Law 117-79, the ALS research program at the Department of Defense, the National Institutes of Health, ARPA-H, and the Centers for Disease Control and Prevention. It is imperative that Congress supports ALS programs to sustain promising research and launch clinical trials that speed access to innovative treatments for people living with ALS today and all those who unfortunately will be diagnosed with ALS, including those at higher risk, such as ALS-gene carriers and Veterans.

In order of priority, we urge Congress to:

1. Invest in clinical research by increasing funding to \$80 million for the ALS CDMRP program at the Department of Defense (ALSRP) in FY2026. In the United States, Veterans are twice as likely to develop ALS. In FY2024, it was reported that ALSRP received \$80 million+ in research proposals that were scored at the fund level; double the Congressionally allocated amount. This meant numerous high-quality research projects for novel ALS therapies were unfunded. If we are to end ALS, a currently terminal, underfunded disease, we cannot let high-quality research go underfunded. We must fund research to understand and find treatments for a disease that is service-connected, has a higher incidence among Veterans, and has direct relevance to the health of our military.

2. Fully fund the *ACT for ALS* at \$100 million for FY2026, specifically allocating \$75 million for the National Institute of Health (NIH) expanded access program under section 2 and \$25 million for the HHS Public-Private Partnership for Rare Neurodegenerative Diseases and FDA Rare Neurodegenerative Disease Grant Program. Any funds that NIH cannot use for expanded access should go towards therapeutic research development to advance new ALS therapies. We also request the FDA continue to exercise its 2019 guidance on regulatory flexibility and to consider patient tolerance for risk in ALS drug approvals.
3. Support NIH funding for ALS research. A reduction in research funding for ALS poses a significant risk to the progress of developing new therapies, identifying biomarkers, and ultimately finding a cure for ALS. Therefore, we request an increase in funding to provide \$180 million in 2026 for pre-clinical and clinical ALS research.
4. Address underfunded research at the Centers for Disease Control and Prevention (CDC). CDC currently receives \$10 million in funds for the National ALS Registry and Biorepository. We request an increase to \$15 million to maintain this program and support research into causes and prevention strategies for sporadic and familial (genetic) ALS that can lower the incidence of ALS, including environmental impact.

These programs are critical to providing hope for those living with ALS and rare neurodegenerative diseases. They are also essential to the pursuit of new treatments and cures for those currently living with these diseases and those diagnosed in the future.

We would like to remind Congress that Veterans are more likely to be diagnosed with ALS than their civilian counterparts. It's for this reason that we recommend the Department of Veterans Affairs ensure access to multidisciplinary ALS care for veterans regardless of geographic location, increase VA opportunities for ALS health professional training, and invest in clinical and informatics resources to enhance VA's ability to partner with outside entities as recommended by the [National Academies of Sciences, Engineering, and Medicine](#).

We urge Congress to act expeditiously on these requests to provide immediate support to the entire ALS community and beyond.

Sincerely,

