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 4, 2026

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 2027 (FY2027) 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 (DoD), the National Institutes of Health (NIH), ARPA-H, the Department of Veterans Affairs (VA), and the Centers for Disease Control and Prevention (CDC). 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. Fully fund the ACT for ALS with at least $100 million for FY2027 to support the law's core programs, including the NIH Expanded Access Program, the NIH Access for ALL in ALS Consortium (ALL ALS) natural history study, the HHS Public-Private Partnership for Rare Neurodegenerative Diseases, and FDA's Rare Neurodegenerative Disease Grant Program and Action Plan for Rare Neurodegenerative Diseases. FDA's responsibilities under the *ACT for ALS* have remained underfunded, and according to the Government Accountability Office, increasing appropriations for these programs is crucial to the law's success. Ensuring at a minimum a full $100 million in appropriations for *ACT for ALS* programs remains critically important to the health and well-being of present and future generations of the ALS community.

2. Invest in clinical research by increasing funding to $80 million for the ALS CDMRP program at the Department of Defense (ALSRP) in FY2027. In the United States, Veterans are twice as likely to develop ALS, yet in FY2025 the program funded only 24% of the high-quality research proposals it received due to limited appropriations. The ALSRP has made significant contributions to the field by investing in high-risk, high-impact research that accelerates the

development of potential new treatments. Its funding spans the full research continuum from foundational bench science to pilot clinical trials and emerging brain-computer interface technology. If we are to end ALS, we cannot afford to leave promising research unfunded. Increased investment is critical to address a service-connected disease with higher incidence among Veterans and direct relevance to the health of our military.

3. Support NIH funding for ALS research. In the past few years, NIH research on ALS has delivered a new therapy, validated new biomarkers and uncovered new genetic links - momentum we must sustain to reach a cure. A reduction in research funding for ALS poses a significant risk to this progress in finding a cure for ALS. Therefore, we request a $20 million increase in funding in 2027 for pre-clinical and clinical ALS research.

4. Address underfunded research at the CDC. CDC currently receives $10 million in funds for the National ALS Registry and Biorepository. We request an increase to $15 million to maintain the largest data repository for ALS and the 80,000 biosamples that support ongoing research. CDC-driven research is advancing the understanding of both sporadic and familial (genetic) ALS - including environmental risk factors - to prevent ALS and lower the incidence of ALS.

5. Ensure the ARPA-H continues to recognize ALS as a priority and sustain the $30 million to support research and clinical trials enabling novel clinical trial designs as well as novel therapy development that have the potential to improve the health of Americans with ALS as quickly as possible.

6. Establish at least ten ALS Research, Education, and Clinical Care Centers (ALS-RECCs) across the country supported by an ALS Center of Excellence to coordinate and conduct research as recommended by the National Academies of Sciences, Engineering, and Medicine 2024 report on Living with ALS. In addition, the Centers will strengthen and better coordinate the specialized ALS workforce necessary to deliver comprehensive, multidisciplinary care, while also building a unified research infrastructure within the VA system to advance innovation and improve outcomes for veterans living with ALS. Implementation of the VA's ALS System of Care remains uneven across the VA system, limiting access to high-quality ALS care and clinical trial participation for our veterans. We request a $9,000,000 investment within the VA to establish and implement these Centers and ensure consistent, high-quality care for veterans living with ALS.

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

Sincerely,

ALS Network

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