

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

The Honorable Kay Granger
Chair
House Committee on Appropriations
H-307 The Capitol
Washington, DC 20515

The Honorable Susan Collins
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 5, 2024

Dear Chair Murray, Chair Granger, Vice Chair Collins, and Ranking Member DeLauro,

On behalf of the ALS community, the undersigned organizations would like to express our appreciation for the support you have provided to help improve outcomes for those living with ALS. Looking forward we would like to reiterate our funding request from last year and ask that Congress increase 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. It is imperative that increased support be provided to launch more clinical trials that speed access to promising research and innovative treatments for people living with ALS today and all those who unfortunately will be diagnosed with this terrible disease in the future.

Specifically, we urge Congress to:

- Fully fund the ACT for ALS at \$100 million for FY25 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 be used for research.
- Further invest in clinical research by increasing funding to \$80 million for the ALS CDMRP program at the Department of Defense in FY2025. In the United States, Veterans are twice as likely to develop ALS. We must ensure that the resources are

available to strengthen ALS research regarding this disease with a higher incidence and direct relevance to the health of our military.

- Increase NIH funding for ALS research activities outside the ACT for ALS. NIH currently estimates it spent \$131 million for these activities in 2023 (for a total of \$206 million on ALS including the ACT funding). We request an increase of funding to provide \$160 million in 2025 to support pre-clinical and clinical research for ALS
- Ensure that ARPA-H continues to recognize ALS as a priority and invest \$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.
- Increase funding and expand 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 this program and support research into causes and prevention strategies that can lower the incidence of ALS

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

