



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

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

The Honorable Susan Collins  
Vice Chairman  
Senate Committee  
On Appropriations  
S-128 The Capitol  
Washington, DC 20510

The Honorable Rosa DeLauro  
Ranking Member  
House Committee  
on Appropriations  
1036 Longworth House Office  
Washington, DC 20515

Dear Chairwoman Murray, Chairwoman Granger, Vice Chairwoman Collins  
and Ranking Member DeLauro:

The ALS community would like to reiterate our funding request from last year and ask that Congress fully fund the Accelerating Access to Critical Therapies (ACT) for ALS Act, Public Law 117-79, specifically allocating \$75 million for the National Institute of Health (NIH) expanded access research program under section 2 and \$25 million for new translational and clinical investments funded by the FDA Neurodegenerative Disease Grants.

Our organizations believe that we need to help as many people with ALS and rare neurodegenerative diseases as possible. That was and is the goal of ACT for ALS.

In particular, the expanded access program (EAP) created by Section 2 of ACT for ALS will help the 90% of people living with ALS now who do not qualify for clinical trials. Before the ACT for ALS, there was no access to promising, investigational treatments that could change the course of their disease for this huge part of the ALS population. These grants will drive forward research by dramatically expanding who we can study and how we understand if a promising treatment has effect throughout the disease course.

The research and regulatory innovation provisions, Sections 3 and 5, in ACT for ALS will help fund new clinical research. They will also help fund translational research that will speed the discovery of new treatments. In addition, they will help drive regulatory advancements for everyone living with ALS and rare neurodegenerative diseases.

- With respect to ACT for ALS, we urge Congress to fully fund the ACT for ALS at \$100 million for FY24 with 75% of the funding allocated each year for expanded access through the Grants for Research on Therapies for ALS Program and 25% of the funding each year should go to funding 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.

We also believe that we need to increase funding for the entire ALS research ecosystem, which includes the ALS research program at the Department of Defense, the National Institutes of Health, ARPA-H, and the Centers for Disease Control and Prevention.

Specifically, we urge Congress to:

- Further invest in clinical research by increasing funding to \$80 million for the ALS CDMRP program at the Department of Defense in FY2024. US Veterans are twice as likely to develop ALS and we need to ensure that the resources are available to strengthen the research regarding this disease with a higher incidence and direct relevance to the health of our military.
- Support significant increases to NIH funding that will result in increased clinical research funding for ALS.

- Ensure that ARPA-H continues to include ALS and enables both research and 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.
- Expand research at the Centers for Disease Control and Prevention and increase funding to \$15 million to research causes and prevention strategies that will lower the incidence of ALS while maintaining the National ALS Registry and Biorepository.

These programs are critical to providing hope for those living with ALS and rare neurodegenerative diseases today. They're 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,

I AM ALS

ALS Association (ALSA)

Muscular Dystrophy Association (MDA)

Les Turner ALS Foundation

Target ALS

CC: Senator Tester

Senator Lisa Murkowski

Senator Chris Coons

Senator Mike Braun

Senator Dick Durbin

Senator Mitch McConnell

Senator Tammy Baldwin

Senator Moore Capito

Senator Boozman

Senator Heinrich

Senator Hoeven

Representative Harris

Representative Bishop

Representative Calvert

Representative McCollum

Representative Aderholt

Representative Carter

Representative McMorris Rogers

Representative Wasserman Schultz

Representative Sewell

Representative Fitzpatrick

Representative Crow

Representative Mike Quigley

Representative Eshoo