Leading ALS Organizations Celebrate Introduction of ACT for ALS Reauthorization Act: Call for Swift Congressional Passage

Washington, D.C., April 8, 2026 – In support of this week's introduction of the *ACT for ALS Reauthorization Act of 2026* (H.R.8205), leading ALS advocacy organizations released the following statement calling for swift passage of the legislation:

"This week's introduction of the *ACT for ALS Reauthorization Act of 2026* is a meaningful milestone in our unified efforts to reauthorize the *ACT* prior to the September 30, 2026, deadline. We are incredibly grateful to Congressmen Quigley and Calvert for their leadership in introducing this bill. Congress must act swiftly to enact this critical legislation.

The *ACT for ALS Act*, enacted in December 2021, has resulted in meaningful and potentially life-changing impacts for the ALS and rare neurodegenerative disease communities. The National Institutes of Health (NIH) ALS Expanded Access program has funded approximately 750 community members with ALS receiving investigational new treatments and has equipped clinics across the United States with the ability to participate in ALS research. The Access for ALL in ALS Consortium (ALL ALS), funded by the NIH through the *ACT for ALS*, is one of the largest and most important efforts to understand and evaluate the natural history of ALS. The Public-Private Partnerships on rare neurogenerative diseases (Accelerating Medicines Partnership ® in Amyotrophic Lateral Sclerosis [AMP® ALS] Program and the Critical Path for Rare Neurodegenerative Diseases Program [C-Path RND]) have made meaningful strides in accelerating data integration, digital biomarkers, and therapeutic development, particularly for ALS, and the FDA's Rare Neurodegenerative

Disease Grants Program has funded over $20 million in research accelerating therapeutic development across the spectrum of rare neurodegenerative diseases.

The legislation also makes refinements to *ACT for ALS* programs in response to report findings to ensure their continued success in the years ahead. All these important advancements may cease to exist unless Congress passes the *ACT for ALS Reauthorization Act*.

Congress must act quickly; the ALS community cannot wait."

Signed:

ALS Arizona
ALS Association
ALS Hope Foundation
ALS One
ALS Network
ALS of Nevada
ALS New Mexico
ALS Northwest
ALS United
ALS United Connecticut
ALS United of Georgia
ALS United Greater New York
ALS United Illinois, Indiana, & Missouri
ALS United Mid-Atlantic
ALS United North Carolina
ALS United Ohio
ALS United Orange County
ALS United Rhode Island
ALS United Rocky Mountain
Answer ALS
Compassionate Care ALS
Hop on a Cure
I AM ALS
Les Turner ALS Foundation
Muscular Dystrophy Association
Project ALS
Target ALS