



May 25, 2021

ALS Organizations Double Down on Their Support for Reintroduced Legislation That Will Accelerate Research and Encourage Access to Critical Investigational Therapies for Those Living with ALS.

Today, leaders in the House of Representatives and Senate reintroduced the *Accelerating Access to Critical Therapies for ALS Act*. The ALS Association, I AM ALS, and the Muscular Dystrophy Association (MDA) endorse the revised legislation with this statement:

“The *Accelerating Access to Critical Therapies (ACT) for ALS Act* builds new pathways to fund early access to ALS investigational therapies, accelerates ALS and rare neurodegenerative disease therapeutic development through a public-private partnership, and increases research on, and development of, interventions for rare neurodegenerative diseases through a new Food and Drug Administration (FDA) research grants program. The ALS Association, I AM ALS, and the Muscular Dystrophy Association endorse this legislation that is a paradigm shift in how therapeutic development, access to treatments, and research has been approached in a fatal, fast-progressing disease like ALS.

The *ACT for ALS* will authorize \$100 million a year over a five-year period to:

- (1) create a new grant program that funds access to investigational ALS treatments currently in development from small biotechnology companies for those patients who cannot participate in clinical trials, while concurrently supporting a research objective on how these investigational treatments impact the disease;
- (2) establish a Health and Human Services (HHS) Public-Private Partnership for Rare Neurodegenerative Diseases between the National Institutes of Health (NIH), the FDA, and eligible stakeholders with a connection to the patient population(s) to advance the understanding of rare neurodegenerative diseases and foster the effective development and evaluation of treatments;
- (3) implement an FDA grant program to fund research and therapy development for ALS and other life-threatening or severely debilitating rare neurodegenerative diseases; and
- (4) commission the publication of an FDA Action Plan to support drugs that improve and extend the lives of people as quickly as possible and facilitate access to investigational drugs for those living with amyotrophic lateral sclerosis and other rare neurodegenerative diseases.

The *ACT for ALS* is championed by Congressmen Fortenberry and Quigley and Senators Coons and Murkowski. We are very grateful for their continued efforts to get treatments and cures to those living with ALS and other rare neurodegenerative diseases as soon as possible. We look

forward to partnering with our powerful patient communities and working with our many champions on Capitol Hill to gain broad, bi-partisan support for this important legislation.

For too long ALS has been an underfunded disease. This lack of investment has stalled discoveries and resulted in far too many lives lost. The *ACT for ALS* brings us one step toward changing that and accelerating the movement to end this disease.”

For questions on the above statement, please contact Brian Frederick, ALS Association, at bfrederick@alsa-national.org, Kathleen Rooney, I AM ALS, at kathleen@iamals.org, or Mark Fisher, MDA, at mfisher@mdausa.org.