



October 29, 2020

Leading ALS Organizations Endorse the Improved *Accelerating Access to Critical Therapies (ACT) for ALS Act*

In response to the introduction the improved *Accelerating Access to Critical Therapies (ACT) for ALS Act* (H.R. 8662 & S. 4867), the ALS Association, I AM ALS, and the Muscular Dystrophy Association (MDA) issued the following statement:

“The ALS Association, I AM ALS and the Muscular Dystrophy Association (MDA) endorse the improved *Accelerating Access to Critical Therapies (ACT) for ALS Act* (H.R. 8662 & S. 4867) as a key step in bringing promising new treatments to patients as quickly as possible while simultaneously expanding access to experimental treatments outside of clinical trials. The revised *ACT for ALS Act* creates a new framework that has the potential to provide expanded access to investigational drugs and accelerate the development and approval process for new therapies and cures. We thank Senators Coons and Murkowski, Representatives Fortenberry and Quigley, and all sponsors for their leadership and collaborative approach.

First, this legislation creates a new grant program that funds access to investigational ALS treatments currently in small biotechnology company clinical trials for those patients who cannot participate, while concurrently researching how these investigational treatments impact the disease. Second, the revised legislation also invests in neurodegenerative disease research through a brand-new Food and Drug Administration (FDA) Rare Neurodegenerative Disease Grant Program. Finally, the *ACT for ALS Act* would establish a Health and Human Services (HHS) Collaborative for Neurodegenerative Diseases jointly led by the FDA and the National Institutes of Health (NIH), the first federal entity explicitly charged with the responsibility to speed the development and approval of therapies for neurodegenerative diseases.

The improved *ACT for ALS Act* brings us one step closer to finding effective treatments for everyone with ALS. We look forward to working with Congressional leaders on Capitol Hill and the entire ALS community as the bill is refined throughout the legislative process to enact the *ACT for ALS Act* as soon as possible.”

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