



Muscular Dystrophy Association urges swift passage of the ACT for ALS by the Energy and Commerce Committee

Washington, D.C., November 17, 2021 – Today, the Muscular Dystrophy Association released the following statement on today’s Energy and Commerce Committee markup of the ACT for ALS:

“In service of the neuromuscular disease (NMD) patient community, the Muscular Dystrophy Association (MDA) thanks Chairman Pallone, Ranking Member McMorris-Rodgers, Chairwoman Eshoo, Ranking Member Guthrie, and all members of the Energy and Commerce Committee for holding today’s markup of the *Accelerating Access to Critical Therapies (ACT) for ALS Act* (H.R.3537). We urge all members to support this legislation during today’s proceedings.

The ACT for ALS should meaningfully increase opportunities for individuals with ALS to access investigational therapies outside of the clinical trials in which they are unable to participate. The legislation creates a valuable new opportunity for the stakeholder community to collaborate with the Department of Health and Human Services (HHS), the National Institutes of Health (NIH), and the Food and Drug Administration (FDA), and commissions a plan from the FDA on regulatory innovations, all intended to speed up creation of new rare neurodegenerative disease treatments. The bill will also create a new grants program to fund millions of dollars of research into needed therapeutic development in rare neurodegenerative diseases.

Earlier this month, the Energy and Commerce Subcommittee on Health unanimously forwarded the legislation favorably to the full Committee with an AINS that ensured 1) an increase in expanded access programs will not have unintended negative effects on clinical trials, 2) a full accounting of the pilot expanded access program is conducted by the Government Accountability Office (GAO), and 3) the smooth operations of the expanded access grants program between HHS and eligible participants will proceed.

We fully support this legislation, including the changes made earlier this month within the AINS, and urge all Committee members to vote YES.

This is a critical step in enacting this impactful legislation, and we are eager to work with Congressman Quigley, Energy and Commerce Committee leaders, and leaders of the House of Representatives to pass the ACT for ALS as soon as possible.”

For questions on the above statement, please contact Paul Melmeyer at the Muscular Dystrophy Association at pmelmeyer@mdausa.org.