May 12, 2026

The Honorable Morgan Griffith,
Chairman
House Committee on Energy and Commerce
Subcommittee on Health
2110 Rayburn House Office Building
Washington, DC 20515

The Honorable Diana DeGette,
Ranking Member
House Committee on Energy and Commerce
Subcommittee on Health
2111 Rayburn House Office Building
Washington, DC 20515

Re: Energy and Commerce Subcommittee on Health Markup of the ACT for ALS Reauthorization Act (H.R.8205)

Dear Chairman Griffith and Ranking Member DeGette:

In service of the neuromuscular disease (NMD) patient community, including those living with amyotrophic lateral sclerosis (ALS) and other rare neurodegenerative diseases, the Muscular Dystrophy Association (MDA) thanks the Energy and Commerce Subcommittee on Health (the Subcommittee) for convening tomorrow's markup. In particular, we are incredibly grateful for the Subcommittee's consideration of the ACT for ALS Reauthorization Act of 2026 (H.R.8205), legislation that will renew and refresh critical ALS and other rare neurodegenerative disease research and drug development initiatives. We ask that you vote to send this legislation to the full Committee.

MDA is the #1 voluntary health organization in the United States for people living with muscular dystrophy, ALS, and related neuromuscular diseases. For over 75 years, MDA has led the way in accelerating research, advancing care, and advocating for the support of our community. MDA's mission is to empower the people we serve to live longer, more independent lives.

The ACT for ALS, enacted in December 2021, ushered in the exact kind of change the ALS and rare neurodegenerative disease community deserves. Notably, the law successfully expanded access to investigational therapies for those with ALS. According to the Government Accountability Office (GAO), approximately 750 people with ALS have received an investigational therapy due to ACT for ALS funding, individuals who were otherwise ineligible to participate in clinical trials and other available treatments were inadequate to alter the progression of their disease. This funding also unlocked the research potential of clinics across the United States, including the very first clinics to participate in ALS expanded access efforts in states like Idaho and Iowa. The law also has funded groundbreaking natural history data collection and analysis through the Access for All in ALS (ALL ALS) Consortium, a crucial endeavor for better understanding the risk factors, etiology, and progression of the disease.

The ACT for ALS also created and continues to fund the Accelerating Medicines Partnership for Amyotrophic Lateral Sclerosis (AMP ALS) as well as the Critical Path for Rare Neurodegenerative Diseases, two key facets of the HHS Public Private Partnership for Rare

Neurodegenerative Diseases created under the law. Both programs seek to speed therapeutic development in ALS and other rare neurodegenerative diseases by accelerating the creation of drug development tools and other approaches to bringing new treatments through clinical trials and to our community.

Finally, the ACT for ALS commissioned the ALS and other Rare Neurodegenerative Disease Action Plan. This plan, published in the summer of 2022, outlined the steps and initiatives the Food and Drug Administration (FDA) would take to accelerate therapeutic development in ALS. The law also created the FDA Rare Neurodegenerative Disease Grants Program, an effort that has funded over $20 million in drug development projects in ALS, Huntington's disease, myotonic dystrophy, ataxias, and more.

ALS remains an unrelenting disease. While progress has been achieved over the past five years, the experience of someone newly diagnosed with ALS today remains far too similar to the experience from five years ago. This is why reauthorizing the ACT for ALS's programs are critical for maintaining the hope and possibility of a life-changing, maybe even life-saving, treatment reaching the ALS and rare neurodegenerative disease community.

The ACT for ALS Reauthorization Act will reauthorize each of these programs while refining and improving upon the original law's approach. This bill will better target the investigational therapies available to the ALS community under the law's expanded access program by ensuring they are showing promising signs of effectiveness as well as allowing potential treatments in phase 2/3 trials to qualify, a necessary fix in today's rare disease drug development ecosystem. The bill will also renew FDA's Action Plan while requiring updates on the progress achieved under the original plan, and will commission a GAO report to evaluate the impacts of the reauthorization.

The ALS community stands united in supporting this legislation – over 25 organizations have called for swift passage of this bill.[1] We urge all Subcommittee members to support the favorable reporting of this legislation to the full Committee. For questions regarding MDA or the above comments, please contact Paul Melmeyer, Executive Vice President, Public Policy and Advocacy, at pmelmeyer@mdausa.org,

Sincerely,

Paul Melmeyer, MPP
Executive Vice President, Public Policy and Advocacy
Muscular Dystrophy Association

[1] "Leading ALS Organizations Celebrate Introduction of ACT for ALS Reauthorization Act: Call for Swift Congressional Passage" – April 8, 2026 - https://www.mda.org/press-releases/leading-als-organizations-celebrate-introduction-of-act-for-als-reauthorization-act-call-for-swift-congressional-passage