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## **FOR IMMEDIATE RELEASE**

### **Muscular Dystrophy Association Celebrates Senate Passage of the ACT for ALS, calls on President Biden to Sign into Law**

**Washington, D.C., December 16, 2021** –The Muscular Dystrophy Association released the following statement on tonight’s Senate passage of the ACT for ALS:

This evening, the Senate passed the *Accelerating Access to Critical Therapies (ACT) for ALS Act* (H.R.3537 and S.1813), sending the legislation to President Biden’s desk following last week’s passage in the House of Representatives. We call on President Biden to sign this legislation into law as soon as possible.

This moment would not be possible without thousands of patient advocates who have spent countless hours reaching out to their Congresspersons asking them to prioritize the ALS and rare neurodegenerative disease communities. Similarly, this bill would not have passed without the leadership of Senators Coons and Murkowski, Congressmen Quigley and Fortenberry, their staff, and leaders across Capitol Hill.

The ACT for ALS would 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 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.

“We look forward to President Biden signing this legislation into law, and to ensuring the promise of this legislation becomes a reality,” said Paul Melmeyer, Vice President of Public Policy & Advocacy for the Muscular Dystrophy Association.

#### **About the [Muscular Dystrophy Association](#)**

For 70 years, the Muscular Dystrophy Association (MDA) has been committed to transforming the lives of people living with muscular dystrophy, ALS, and related neuromuscular diseases. We do this through [innovations in science](#) and [innovations in care](#). As the largest source of funding for neuromuscular disease research outside of the federal government, MDA has committed more than \$1 billion since our inception to accelerate the discovery of therapies and cures. [Research we have supported](#) is directly

linked to life-changing therapies across multiple neuromuscular diseases. [MDA's MOVR](#) is the first and only data hub that aggregates clinical, genetic, and patient-reported data for multiple neuromuscular diseases to improve health outcomes and accelerate drug development. MDA supports the [largest network of multidisciplinary clinics](#) providing best-in-class care at more than 150 of the nation's top medical institutions. Our [Resource Center](#) serves the community with one-on-one specialized support, and we offer educational conferences, events, and materials for families and healthcare providers. [MDA Advocacy](#) supports equal access for our community, and each year thousands of children and young adults learn vital life skills and gain independence at [summer camp](#) and through recreational programs, at no cost to families. During the COVID-19 pandemic, MDA continues to produce virtual events and programming to support our community when in-person events and activities are not possible. MDA's COVID-19 guidelines and virtual events are posted at [mda.org/COVID19](#). For more information, visit [mda.org](#).

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