



Three Leading ALS Organizations Celebrate House Passage of *ACT for ALS*, Call for Swift Senate Action

Washington, D.C., December 8, 2021 – Today, I AM ALS, The ALS Association and the Muscular Dystrophy Association released the following statement on today's passage of *ACT for ALS* in the House of Representatives:

"I AM ALS, The ALS Association and the Muscular Dystrophy Association (MDA) celebrate today's passage of the *ACT for ALS* (H.R.3537/S.1813) in the House of Representatives and call for immediate Senate action to send this bill to the President's desk. We are grateful to our champions Congressmen Quigley and Fortenberry and leaders throughout the House for making today's passage a reality.

With more than 330 House and 50 Senate cosponsors, this critical bill has more cosponsors than any bill introduced in Congress this year. Today's vote brings this legislation one step closer to making a meaningful difference in the lives of those living with ALS and other rare neurodegenerative diseases.

ACT for ALS creates a new grant program that funds access to investigational ALS treatments for people living with ALS who cannot participate in clinical trials, while also supporting research on treatment safety and ALS progression.

The legislation invests in neurodegenerative disease research through a brand-new Food and Drug Administration (FDA) Rare Neurodegenerative Disease Grant Program. This program is critically important to keeping FDA and other federal agencies moving urgently to find treatments and cures that can be approved by the FDA, covered by health insurance and made available to all.

Finally, the *ACT for ALS* would establish a Health and Human Services (HHS) Public-Private Partnership for Rare 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 rare neurodegenerative diseases.

'Today, we celebrate the fierce community of advocates who were relentless in making *ACT for ALS* the most cosponsored bill in this Congress,' I AM ALS Director of Science and Policy Dr. Megan Miller said. 'Today's overwhelming support and passage in the House of Representatives is a direct result of the advocates' unwavering determination to improve the lives of people living with ALS today and in the future. I AM ALS stands united with them in calling for immediate action in the Senate. It is time we act with the urgency this disease requires.'

The ALS Association Chief Mission Officer Dr. Neil Thakur said, 'We have worked closely with Congress and advocates on this measure to provide funding for early access to ALS investigational therapies as well as new funds to FDA for ALS research to develop cures and treatments. People with ALS can't wait, and passage of this bill is urgently needed.'

‘Today’s overwhelmingly bipartisan House passage of the *ACT for ALS* further emphasizes the importance of enacting this legislation as soon as possible. Now it is time for the Senate to act. The Muscular Dystrophy Association stands behind this legislation and is eager to work with the bill sponsors and Senate leaders to make this a reality,’ said Paul Melmeyer, Vice President, Public Policy and Advocacy, Muscular Dystrophy Association.”

For questions on the above statement, please contact

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