



Three Leading ALS Organizations Celebrate President Biden Signing the ACT for ALS into Law

Washington, D.C., December 23, 2021 – Today, I AM ALS, The ALS Association and the Muscular Dystrophy Association released the following statement on President Biden signing Accelerating Access to Critical Therapies for ALS (ACT for ALS) bill into law:

"I AM ALS, The ALS Association and the Muscular Dystrophy Association (MDA) join together to celebrate President Biden signing ACT for ALS (H.R.3537/S.1813) into law. We look forward to working closely with the Biden Administration to ensure all aspects of this legislation are implemented fully and swiftly.

With today's signing into law, ACT for ALS will create 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.

This law invests in neurodegenerative disease research through a brand-new Food and Drug Administration (FDA) Rare Neurodegenerative Disease Grant Program. This program will be critically important to keep the 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, ACT for ALS will 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, hope became tangibly real through this law for every person living with and impacted by ALS,' I AM ALS Director of Science and Policy Dr. Megan Miller said. 'We celebrate the tens of thousands of advocates who successfully drove this legislation forward, and we applaud Congress and the President for acting in the interest of the ALS community. We look forward to working with HHS, FDA and NIH to establish successful programs and ensure promising therapies get into the bodies of those living with ALS as soon as safely possible.'

The ALS Association Chief Mission Officer Dr. Neil Thakur said, 'We thank all the people living with ALS, their families, and ALS advocates who worked together to enact this critical legislation. We also thank President Biden and Members of Congress for this bill, which will speed the discovery of new treatments for everyone living with ALS, and expand access to experimental therapies. We look forward to working with Congress and the Biden administration to fully implement every aspect of this bill as soon as possible.'

'Today we celebrate President Biden signing ACT for ALS into law, the culmination of months of extensive advocacy from the ALS and rare neurodegenerative disease communities,' said Paul

Melmeyer, Vice President of Public Policy and Advocacy for the Muscular Dystrophy Association. 'Now we must turn our attention toward fully funding the programs within the law, and implementing them to their fullest extent, all to accelerate treatment development and access for the ALS and rare neurodegenerative disease communities.'"

For questions on the above statement, please contact

Theresa Garner, I AM ALS, at Theresa@iamals.org

Brian Frederick, The ALS Association, at brian.frederick@als.org

Mary Fiance, MDA, at press@mdausa.org