



Three Leading ALS Advocacy Organizations Call on Congress to quickly pass *Accelerating Access to Critical Therapies (ACT) for ALS Act*

I AM ALS, The ALS Association and the Muscular Dystrophy Association (MDA) join the 325 members of the House of Representatives and 34 Senators supporting this bill, and we call for immediate passage of the ACT for ALS (H.R.3537/S.1813). Passing this bill will bring hope to people living with ALS while also improving our understanding of this and other devastating neurodegenerative diseases.

This critical bill is the only piece of legislation yet to receive a vote that has more than 350 signatures across the aisle, with all parties agreeing that it must be brought to the floor for a vote.

First, this legislation 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.

Second, the revised legislation also 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, *ACT for ALS Act* would establish a Health and Human Services (HHS) Collaborative 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.

"Time is the most valuable resource to people living with ALS, a rapidly progressive and 100% fatal neurodegenerative disease. The ALS community has watched this bill be reintroduced twice, and in that time hundreds of lives have been lost waiting for access to treatments," I AM ALS Director of Science and Policy Dr. Megan Miller said. "We are elated to see immense bipartisan support throughout Congress and commend our ALS champions for their commitment to making ACT for ALS a reality for those living with ALS now."

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."

"This widespread, bipartisan support unequivocally shows it is time to enact the legislation. The Muscular Dystrophy Association stands behind this legislation and is eager to work with the bill sponsors and Senate and House leaders to enact this bill as soon as possible," said Paul Melmeyer, Vice President, Public Policy and Advocacy, Muscular Dystrophy Association.