

Statement for the Record

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Accelerating Access to Critical Therapies (ACT) for ALS Act (H.R. 3537)

Statement to House Committee on Energy and Commerce

Subcommittee on Health

November 4, 2021

On behalf of the more than 20,000 Americans living with amyotrophic lateral sclerosis (ALS) and their loved ones whom we serve each year, The ALS Association urges Congress to pass the Accelerating Access to Critical Therapies (ACT) for ALS Act (H.R. 3537).

The ALS community urgently needs new therapies to be developed, approved and made accessible to people living with ALS. We must dramatically speed and increase the number of clinical trials for ALS drugs while at the same time support expanded access to promising new investigational drugs outside of clinical trials. The ACT for ALS Act achieves this balance in purpose and funding.

First, it authorizes a unique grant program to provide expanded access to experimental drugs in certain circumstances. Because expanded access drugs are not covered by insurance, federal funding is authorized. This expanded access program offers hope and promises to provide data that can inform scientific research.

Second, the bill calls for research on ALS to be funded directly by the FDA. Not only will this approach encourage more clinical trials, but it will also help the FDA directly address the research and regulatory questions that makes overseeing ALS drug discovery so slow. A bigger and faster ALS drug discovery enterprise will lead to additional effective drugs approved by the FDA, and thereby available to everyone with ALS with insurance coverage.

Third, the bill calls for a new Collaborative for Rare Neurodegenerative Diseases at the Department of Health and Human Services (HHS) to coordinate federal efforts on developing and approving effective treatments and cures. That could mean faster and more impactful efforts to find effective treatments for ALS.

We strongly support the Accelerating Access to Critical Therapies (ACT) for ALS Act (H.R. 3537) and urge this committee and Congress to support this bill. Speed matters! Help us end ALS!



OUR VISION: Create a world without ALS.

OUR MISSION: To discover treatments and a cure for ALS, and to serve, advocate for, and empower people affected by ALS to live their lives to the fullest.

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About ALS

Amyotrophic lateral sclerosis (ALS) is a progressive neurodegenerative disease that affects nerve cells in the brain and the spinal cord. About 90 percent of ALS cases occur without family history. The remaining 10 percent of ALS cases are inherited through gene mutations. Research indicates ALS is more prevalent in people who have served in the U.S. military.

As ALS progresses, people lose the ability to move, eat, and breathe on their own. Most people who develop ALS are between the ages of 40 and 70, but ALS can strike anyone. Because it is a complex disease, it takes on average twelve months to receive a final diagnosis. Most people with the disease die within 2-5 years of diagnosis of respiratory failure. ALS impacts the whole family as spouses, children, siblings, and friends seek to provide the critical support needed.

About the ALS Association

Established in 1985, The ALS Association is the only national nonprofit organization fighting ALS on every front. By leading the way in global research, providing assistance for people with ALS through a nationwide network of chapters, coordinating multidisciplinary care through certified clinical care centers, and fostering government partnerships, The Association builds hope and enhances quality of life while aggressively searching for new treatments and a cure.

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