Brian Wallach, Person Living with ALS and Co-Founder of I AM ALS

& Sandra Abrevaya, Caregiver and Co-Founder of I AM ALS

Hearing Testimony

House Energy & Commerce Subcommittee on Health

2123 Rayburn House Office Building
10:15 AM
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Chairman Guthrie, Chair Griffith, Ranking Members Pallone and DeGette, and Members of the Subcommittee:

My name is Brian Wallach. I am 45 years old, and I have been fighting ALS for eight years. I am joined today by my wife and caregiver, Sandra Abrevaya. Together, we are the co-founders of I AM ALS - a patient-created and led organization representing the thousands of people living with ALS, their families, and their caregivers. We are here with one simple and urgent request: reauthorize ACT for ALS - it is the single biggest investment in ALS research and reauthorizing it is our best chance at finding a cure.

I was diagnosed with ALS in 2017. In the nearly 160 years that Amyotrophic Lateral Sclerosis has had a name, the outcome has been the exact same for every generation: there are no survivors. Ever. ALS has killed every single person it strikes. Many of you heard from actor Eric Dane earlier this year when he joined the I AM ALS movement and spoke with legislators about the importance of reauthorizing ACT for ALS. Tragically, ALS took his life 3 months ago. I know that if he were still alive he would be sitting here speaking beside me.

I am here as a former attorney in the White House Counsel's Office, someone who has worked alongside this very Committee, and then as a federal prosecutor. I am here as a person living with ALS - a husband, a father to two amazing daughters, and as a son. But above all else, I am here as the founder of the largest movement in ALS in our lifetimes - a coalition of patients, caregivers, researchers, doctors, and advocates who know what is needed to find a cure.

I am deeply grateful for this Committee's and Subcommittee's bipartisan leadership in passing the Act for ALS known as the Accelerating Access to Critical Therapies for ALS Act in 2021. The law addressed numerous gaps in research, infrastructure, and access, passing Congress with nearly unanimous, bipartisan support. It is the largest investment in ALS research in history and established an Expanded Access Program to allow promising therapies to reach patients as

quickly as possible. And it is urgently needed because the FDA's standard, decade-long drug approval process does not work for ALS, a disease where life expectancy is only 2–5 years. ACT for ALS stands as a meaningful testament to how an entire community can motivate Congress to create a clearly designed program to address a critical need, the Congress can unite to act expeditiously in the interests of the people.

Today, the program provides patients with promising new therapies that are extending lives whose pleas were ignored before Act for ALS. It gives researchers access to more data from the whole community - not just the lucky few eligible for clinical trials. I want to put a fine point on that link between the EAP and research; receiving these grants are required to collect and share data from EAP participants through NIH approved protocols, helping to accelerate research and inform future approvals. Proof of the value is that FDA recently requested that a drug company provide data from one EAP to supplement their trial data during the approval process. Furthermore, the Act provides the entire ecosystem of neurological disease, a model for how to attack everything from ALS to Parkinson's to Huntington's to Alzheimer's. Simply put, this law is working. It is enhancing survivability for hundreds of patients across the country and – in some cases, like my own – actually reversing symptoms. I am alive and able to be here with you today, in part, because of a drug that is in an ACT for ALS Expanded Access Program. This means more time with my family, milestones with my children, and more time as we seek a cure.

In just four years, the Act forced the NIH and FDA to collaborate and coordinate for the first time ever, driving unprecedented progress toward a cure. It has gotten us closer to that cure by offering potential therapies to patients who never before had access, producing invaluable data on understudied populations, funding a coordinated research ecosystem, and facilitating the critical collection of biological samples and information-sharing platforms.

We are on the cusp of changing this disease's trajectory, and there is strong precedent in recent US history for continuing this robust, ambitious research. When we look back at the 1980s, an HIV/AIDS diagnosis was a near-certain death sentence, with an average life expectancy of just one year. However, the federal government made a historic, sustained commitment to research—investing billions of dollars through the NIH and establishing collaborative drug discovery programsThat sustained federal funding directly led to the discovery of AZT (1)and the subsequent development of the antiretroviral drug cocktails that transformed HIV from a fatal disease into a manageable chronic condition, allowing patients to live near-normal lifespans

We are at that exact same precipice with ALS today. Just as Congress did not abandon HIV/AIDS researchers before they found the cocktail that saved millions of lives, you must not abandon ALS patients now. Reauthorizing the ACT for ALS ensures that the federal government maintains the sustained, aggressive investment required to find the "cocktail" of therapies that will finally make ALS a survivable disease.

Furthermore, reauthorization of ACT for ALSis not just an investment in curing one disease. ALS is the tip of the spear to unlocking treatments for the most devastating neurodegenerative disorders of our time. Over the last decade, science has revealed profound genetic and cellular similarities across ALS, Alzheimer's, Parkinson's, and Huntington's diseases. For example, the toxic buildup of the TDP-43 protein, which occurs in 97% of ALS patients, is also a prominent feature in up to 70% of Alzheimer's cases.(2) Similarly, researchers are finding that the oxidative stress and protein accumulation mechanisms driving ALS are the exact same biological pathways destroying neurons in Parkinson's and Huntington's. By funding aggressive, targeted research into ALS through this Act, you are effectively funding the foundational science needed to develop therapies, preventions, and cures for the millions of Americans suffering from Alzheimer's and Parkinson's.

I will close by addressing a recent GAO study on the ACT for ALS, which noted that the full findings are not yet known because the research funded by the NIH and FDA is early and still ongoing. To that, I must respectfully point out a basic scientific reality: the ACT for ALS was only signed into law in December 2021. It has been less than five years. In the world of medical research, the average clinical trial for a complex neurological disease takes anywhere from nine to twelve years to complete from Phase I to Phase III.(3) It is scientifically impossible to have realized the "full effects" of this legislation in such a short window, and the infrastructure funded as part of this law actually speeds our ability to learn.

The ACT for ALS is a cornerstone of our efforts to defeat this disease, and I am here today to urge you to swiftly pass H.R. 8205, the ACT for ALS Reauthorization Act, introduced just last week by Representatives Mike Quigely and Ken Calvert. Unless ACT for ALS is reauthorized by Congress, we lose these vital research programs and people living with ALS lose access to potential therapies. Passing H.R. 8205 isn't just important—it's urgent. Lives depend on it.

When I last appeared before this Subcommittee in 2021, I wondered aloud whether that testimony would be my last. Thanks to the ACT for ALS, I no longer wonder. I now believe - with every fiber of my being - that I could be part of the first generation to survive this disease. That is because of you. Because of your commitment, your leadership, and your willingness to invest in turning ALS from a 100% death sentence into something we can live with instead of die from. Please do not stop now.

What you did 5 years ago has made it possible to rewrite the ALS story. Now, help us write the next chapter. Thank you.

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1.https://www.niaid.nih.gov/diseases-conditions/antiretroviral-drug-development

2.https://targetals.org/news/similarities-in-neurodegenerative-disorders-may-lead-to-new-common-therapies/

3. whats-the-average-time-to-bring-a-drug-to-market-in-2022