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

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

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Chairman Guthrie, Chair Griffith, Ranking Members Pallone and DeGette, and Members of the Subcommittee: We are deeply grateful for this Committee's and Subcommittee's bipartisan leadership in passing Act for ALS, known as the Accelerating Access to Critical Therapies for ALS Act in 2021.

For those of you less familiar with ALS, let me share something.

Today, there is a chance that you could step out of this building and get hit by a car. I think we all spend an appropriate amount of time worrying about that kind of thing. We teach our kids how to look both ways when they cross the street and we acknowledge the risk of something like that happening in our lifetime.

What we don't realize is that our chances of getting diagnosed with ALS are higher than our chances of getting hit by a car. Everyone in this room is more likely to get ALS than to get hit by a car. And for the last 160 years, there has never been a survivor of ALS. So why do we take precautions to avoid and survive getting hit by a car but we don't take precautions to avoid and survive ALS? That is what we are here to talk about today.

Let me introduce my husband, Brian Wallach who has ALS. He is a living miracle. Only 15% of patients live 5 years past diagnosis. He has been living with ALS for eight years.

He cannot move or speak anymore but he can use his eyes to type and his mind is operating at full speed. Under very difficult circumstances, we left our 8 and 10 year old daughters at home with my parents and have flown from Chicago to meet with you today. Brian is not just a person living with ALS - he is here as the founder of the largest movement in ALS in our lifetimes. I AM ALS is a coalition of patients, caregivers, researchers, doctors, and advocates who know what is needed to find a cure.

Brian speaks: 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.

Brian is a former federal prosecutor and former White House lawyer, who helped write Act for ALS with a core of dedicated champions in Congress in 2021. Why did he do it?

1) Because there was not enough research funding.
2) Because there was no way for patients who couldn't get into clinical trials to get access to life extending treatments

I am going to tell you now how Act for ALS is solving all of these problems. And how it is our best shot at curing ALS.

First, Act for ALS is the single biggest funding mechanism for scientific research in ALS in history.

If we want ALS to be prioritized and to drive to a cure there is no other funding vehicle that will get us there faster. Period. Anyone who stands in the way of Act for ALS reauthorization is standing in the way of our best shot at survival.

Let me tell you how it is advancing scientific research.

- A survey of clinical trial sites showed that because of ACT for ALS, 25% of all clinical trial sites were able to offer Expanded Access Programs to patients for the very first time and 50% of clinical trial sites reported that funding helped increase their research capacity. The headline here is that clinical trial sites across the country have been able to do significantly more research because of this law.
- This law has also funded one of the largest natural history studies for those with ALS and at risk for developing ALS.
- And today, Dr. Jinsy Andrews, the co-chair for NEALS- the leading clinical trial coalition in ALS- has come to join us in DC to reauthorize Act for ALS. She asked that we share that this funding is critical to maintain the momentum of research to accelerate the path to more treatments for ALS.

Next, let me tell you how it is keeping people with ALS alive today through the Expanded Access Program:

- There is a horrible thing that happens today to people with ALS. It often takes years to get diagnosed. And once you are finally diagnosed and told you are going to die you often can't get into clinical trials with promising treatments because you have had symptoms for "too long"
- This law has changed this. Today when patients no longer qualify for clinical trials they now have another option to get access to the treatment. And it's called an Expanded Access Program. These are breakthrough treatments that are keeping patients alive today and the Expanded Access Program in this law is what is making this possible. There is huge demand for this expanded access program and there are waitlists across the country - without this law getting reauthorized, patients across the country will lose access to these critical treatments.
- And the goal continues to be to get treatments through the FDA approval process. In fact, ACT for ALS is providing additional data that is potentially making that FDA process easier. Today, a therapeutics company with a promising ALS treatment has critical additional data that could help on its approval pathway with FDA.

Here is where the law gets even more innovative. The Expanded Access Program is not only keeping people alive today - it is an incredibly unique way to accelerate research. And not just for ALS but for all neurodegenerative diseases - Alzheimer's, FTD, Parkinson's and beyond.

- Because of the Expanded Access Program, every single participant has to submit their blood to a biobank. Guess what

that blood bank has turned into? The single biggest blood bank of ALS biomarker and patient samples ever achieved.
- Guess who else that blood bank helps? Scientists working on every other neurodegenerative disease. If I want to test the validity of an Alzheimer's diagnostic test, I can go and use blood from the ALS blood bank as a neurological control and get an answer faster.

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 neurodegenerative diseases as a category - FTD, Alzheimer's, Parkinson's and beyond.

There is no other country in the world that is doing this. This is American leadership that cannot and has not been matched anywhere else in the globe.

My husband asked me to close by sharing this from him:

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 that I can be a part of the first generation to survive this disease. That is because of you. 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 by passing ACT for ALS. Thank you.