Brian Wallach
Co-Founder, I AM ALS
Outside Public Witness Written Testimony
House Appropriations Subcommittee on Labor, Health and Human Services, Education and Related Agencies
Committee on Appropriations
United States House of Representatives
Regarding FY2023 Health and Human Services and Food and Drug Administration
May 26, 2022

Chairwoman DeLauro, Ranking Member Cole: thank you for the opportunity to speak to you once again about the fight to end ALS. My name is Brian Wallach, I am forty-one years old, and I have been living with ALS for almost five years now. Truth be told, when I first testified before you in 2019, I did not think I would be alive today to speak with you. I am one of the lucky ones, as eighty-five percent of those diagnosed this same year as me are dead.

Thanks to you and the other amazing champions on the Hill, we have made real progress since I first testified before you. Thank you for working to pass and fund the Act for ALS and for recognizing that ALS should be part of the mission of the new ARPA-H. Three years ago, you told me you would do everything in your power to fight for a cure and you have kept that promise. For that I am humbled, but we still have miles to go before we rest.

May is ALS Awareness Month in the US. On May 12, I AM ALS and hundreds of ALS advocates gathered in DC a mile away from the Capitol to plant thousands of flags for those living with ALS and those we have lost. This is the reality of ALS today. For me, my reality is that I can now barely speak, and am mostly confined to a wheelchair, and can no longer raise my arm. But I am still here, and will keep fighting as long as I breathe.

Today, I want to say how grateful the ALS community is to you and your colleagues for what you have done over the last three years. Just five months ago, Congress passed by a vote of 523 to 3 ACT for ALS.

By passing ACT for ALS, Congress, President Biden and the ALS community made clear that the FDA and NIH must act now to implement these programs, most importantly the expanded access grant program. As President Biden said during the December signing ceremony of the bill, "The law invests $100 million annually for the next five years to do three important things: First, it directs the Department of Health and Human Services to issue grants that support research on — and the access to promising new therapies for patients who don't make it into clinical trials. This means hope for patients who would otherwise have no access to treatments that could possibly work for them." "God willing, we're going to make real progress."

The expanded access grant program was designed to serve those living with ALS NOW, while also improving our understanding of ALS for those who will be diagnosed in the future. Earlier this year, you appropriated $25 million to make this program real, and on May 12, NINDS released the Funding Opportunity Announcement for those funds.

I am here today to ask you to build upon this momentum by fully funding **ACT for ALS** for the 2023 fiscal year. Fully funding ACT for ALS means that we need to appropriate $100 million in fiscal year 2023, including $75 million for the expanded access grant program. This funding is desperately needed by those who are dying from ALS right now. This funding will not only change the course of the disease for those with ALS right now, but also the course of ALS overall. It is critical that we fully fund ACT right now so that NINDS and the FDA can move forward aggressively to implement the programs in ACT that will transform not only ALS but also countless rare and neurological diseases.

We urge the Agencies to work with the same urgency as Congress has so that we can make real the hope that ACT for ALS embodies for those who have suffered in the shadows and those who have been left to die for too long. The research and regulatory innovations in ACT for ALS will help fund new clinical trials, discover new treatments, and drive regulatory advancements for millions of Americans.

The ALS community, inclusive of clinicians, clinical researchers, people living with and impacted by ALS, and advocacy organizations are united in their support of expanded access programs, as they have the power to help those living with ALS right now and to transform ALS research going forward. As NIH and FDA create and execute on the expanded access grant program mandated by ACT for ALS, we ask the Agencies to incorporate the set of recommendations the ALS community provided to them this month, which I have attached to my testimony.

I also ask for your support in ensuring that ALS research is robustly supported by NIH and by the Department of Defense. These research programs are critical to furthering our understanding of ALS and unlocking treatments for ALS, as well as Alzheimer's, Parkinson's, Multiple Sclerosis, and beyond.

Because of your tireless efforts and support, there is real hope for those living with ALS and rare neurodegenerative diseases today, as well as those who will be diagnosed in the days, months, and years ahead.

Thanks to you, the path toward ending ALS is clearer, but there is much work to do. On behalf of the ALS community, I thank you and look forward to working with you to turn ALS from always fatal to chronic, and then to end it once and for all.