IAM ALS



Get In. We're Ending ALS

"Nothing good is easy, but everything good is worth fighting for." - Brian Wallach, I AM ALS Co-Founder

What We're Up To

What a week! Last week's Congressional Hearing with the FDA was huge for the ALS community. Our co-founders, Brian and Sandra, testified at the hearing, but their inspiring speech was just one of many that day. Watch their testimony <u>here</u>, and the full hearing <u>here</u>.

Thank the Speakers

So many amazing representatives spoke at last week's hearing. Thank them in a tweet by clicking below.

THANK YOU!

COMMUNITY UPDATES



Clinical Trial Team

There are now 3 clinical trials that have a five star rating! This team created the Patient-Centric Trial Design (PaCTD) Rating Criteria for the purpose of influencing clinical trial design. Cytokinetics' Reldesemtiv trial incorporated humane and efficient procedures from the start. Check out their full rating <u>here</u>.



Community Outreach Team

This team continues to work with corporations to host panels of people impacted by or living with ALS. Join their efforts <u>here</u>.

Legislative Team



This team is riding the wave from last week's Congressional hearing and are sending out videos from the hearing to all their representatives. Check out Brian and Sandra's passionate testimony <u>here</u>.



Many Shades of ALS Team

This team is creating a social media campaign to recruit more members. To learn more about this team and join them, click <u>here</u>.



Thank You Squad

This team is thanking members of the House Energy and Commerce Health Subcommittee for holding last week's hearing. Help them by thanking these representatives on Twitter, with our handy form <u>here</u>.



Veterans Team

This team submitted an abstract for a poster at the **International Symposium on ALS and MND**. The poster would focus on veterans with ALS and suicidal ideation.



Meet Zamir. Zamir is an incredible father and a regular at I AM ALS social hours. He has also served on the Community Review Team. Read more about this incredible person <u>here</u>.

WHAT'S COMING UP?

NORD – Genetic Counseling for Rare and Undiagnosed Conditions

Join this meeting to hear perspectives from genetic counselors and parents about how genetic counseling can be beneficial. This webinar is intended for patients, caregivers, families and the general public. **Register**

ALS Drug Development Webinar Series Part 5: Preclinical

Development of Potential Therapies

This webinar is the fifth installment of the NEALS webinar series on ALS drug development moderated by Dr. Richard Bedlack from Duke's ALS Clinic. In this webinar, Dr. Bowser and Dr. Lagier-Tourenne will discuss the preclinical development of potential therapies. **Register**

SEE ALL EVENTS



I AM ALS is a patient-led community that provides critical support and resources to patients, caregivers and loved ones. It empowers advocates to raise awareness and lead the revolution against ALS in driving the development of cures. Learn more at iamals.org.



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