I AM ALS

Get In. We're Ending ALS

"To hope is to be human. Never give up hope."

- Brian Wallach, I AM ALS Co-Founder

What We're Up To:

I AM ALS just launched a new and improved version of ALS Signal, where users can explore ALS clinical research, trials and studies. It now has a **Genetic ALS Observational Studies** tab, including ongoing and upcoming ALS observational studies being conducted around the world for ALS gene carriers and people related to someone with familial ALS or ALS caused by a specific genetic mutation. How cool is that? Check it out here.

Sign the OLE Petition

Help make open-label extensions a part of every ALS clinical trial.

ADD YOUR NAME

COMMUNITY UPDATES

Clinical Trials Team

This team had an amazing discussion about Expanded Access Programs (EAPs) with Alison Bateman-House, MPH PhD. Listen to the conversation here.

Community Outreach Team

This team has been working on their #ALSisEverywhere social media campaign, posting photos in their t-shirts in interesting places across the country to raise awareness about ALS. Check out this example from our very own Lisa McMullen!

Familial ALS Team
This team hosted some amazing law professors to talk about genetic nondiscrimination laws. Watch their conversation **here**.

Legislative Affairs Team
This team continues to push for ACT for ALS and is now focusing primarily on bringing Senators on board as co-sponsors. Use our **Legislation Tracker** to find out if your Senator has co-sponsored ACT for ALS.

Many Shades of ALS Team
Maceo Carter, a founding member of this team, spoke with **Chelsea Carter, MPH, PhD** about racism and bias within the ALS landscape. Watch their incredible conversation **here**.

Thank You Squad
This team created a virtual thank you collage for the Energy and Commerce Health Subcommittee. Check out their beautiful signs (and faces) **here**!

Community Spotlight: Lakeia Nard Lakeia is a tireless advocate for her son, King'Nazir, who has juvenile ALS. Lakeia recently joined the Many Shades of ALS team, but she was an advocate long before finding I AM ALS; Melanin Children Matter LLC was founded in her son's honor servicing children, healing families and educating society while enhancing awareness surrounding childhood rare diseases. Check it out at **www.melaninchildrenmatter.org**.

WHAT'S COMING UP?

Caregiver Focus Groups

I AM ALS is hosting focus groups to learn from those who are currently caring for or previously cared for someone with ALS. We hope to learn from you about your concerns as a caregiver and your experiences with home healthcare.
See times and sign up **here**.

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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