Get In. We're Ending ALS

What We're Up To

On October 26th, ALS advocates from across the country showed up in force at the Senate Aging Committee's hearing, "Unlocking Hope: Access to Therapies for People with Rare, Progressive, and Serious Diseases." The hearing was focused on the Promising Pathway Act, a piece of legislation several years in the making that this community has pushed for tirelessly. Read our full post-hearing update here: https://iamals.org/updates/update-promising-pathway-act-senate-hearing-sheds-light-on-the-challenges-of-getting-access-to-treatments-for-diseases-like-als/

Get This Bill Passed!

Co-sponsors are starting to rack up in the Senate for the Promising Pathway Act. Find out if your Senators are on the list – and if they aren't, use this action to ask for their support!

CONTACT YOUR SENATORS

COMMUNITY UPDATES

Clinical Trials Team

This team has updated the PaCTD Rating System for clinical trials, and just published a new PaCTD rating based on these new criteria for Ibudilast (NCT04057898) from MediciNova. Check it out: https://iamals.org/patient-centric-trial-design-pactd-rating-criteria/

Community Outreach Team

The Community Outreach Team is hosting a Podcasting Panel on November 14th from 3-4:30 PM ET. This panel will feature ALS podcasters sharing about their processes and experiences. You can sign up here! https://iamals.org/action/podcasting-panel/

Familial ALS Team

Join the I AM ALS Familial Team! This welcoming and driven team is looking for new members to aid in their advocacy efforts. You can join here: https://iamals.org/action/familial-als-team/

Legislative Affairs Team

This team has been reaching out and meeting with Senate offices expressing appreciation for their support and invited them to the recent Senate Committee on Aging meeting about the Promising Pathway Act (PPA) (H.R.4408/S.1906). To help this amazing team advocate effectively for ALS-related legislation, click here to become an I AM ALS legislative constituent. They need people from states and congressional districts all across the country, in other words… they need you!

Many Shades of ALS Team

The Many Shades of ALS Team invites you to attend the next installment of their Let's Talk About It mental health series, this time focusing on navigating the holidays with ALS. The panel will take place November 6th from 6-7:15 PM ET, and you can sign up here! https://iamals.org/action/lets-talk-about-it-november/

The Write Stuff

Check out the latest blog postings from our inspirational and empowering writers: Traveling with ALS (and other disabilities), I taught my son to shave today, Retired by ALS. Learn more or join this warm and welcoming group of writers as they educate others and raise awareness of ALS both within and outside of the ALS community: https://iamals.org/action/the-write-stuff-team/

Veterans Team

Speaking of legislation, this team has been hard at work pushing the Justice for ALS Veterans Act. As a refresher, this bill will extend increased Dependency and Indemnity Compensation (DIC) paid to surviving spouses of veterans who die from ALS, regardless of how long the veterans lived with ALS. Huge shoutout to our friends at **Paralyzed Veterans of America** who have been working tirelessly to get this passed. Learn more and contact your Congresspeople about the bill: **https://iamals.org/legislation/justice-for-als-veterans-2023/**

Our next monthly support group for people who have lost loved ones to ALS will take place on Wednesday, November 1st. This group offers community as attendees are processing grief and other emotions. The group meets from 1 - 2pm ET. Sign up here for this support group, or any of the other groups listed: **https://iamals.org/action/join-a-support-group/**

In Memoriam: Scott Blackwood

We are deeply saddened to share the passing of Scott Blackwood. Scott was a teacher, a writer, a mentor, a father, a husband, a son, and a friend to so many. To quote Scott's obituary, “He was, for many of us, the best person we have known.” He will be terribly missed. Read the full obituary here: **https://www.hamlar-curtis.com/obituary/william-blackwood**

WHAT'S COMING UP?

Annual Global Clinical Trials Update - November 2nd, 7 - 8am ET

This webinar, presented by the International Alliance of ALS/MND Associations, will provide information on ALS/MND treatments currently in Phase 3 Clinical Trials. Attendees will hear directly about timelines, where the sites are, other programs offered, and who to contact if more

information is needed.
Register

Let’s Talk About It - November 6th, 6 - 7:15pm ET

The Many Shades of ALS Team presents the latest installment of their Let's Talk About It mental health series, this time focusing on navigating the holidays with ALS.
Register

Upcoming *No Ordinary Campaign* Screenings

October 29 - Virginia Film Festival
Culbreth Theatre, 2pm ET
Learn more/Register

November 8 - ReelAbilities Film Festival - New Jersey
St. Peters University, Pope Lecture Hall, 11am ET
Learn more/Register

November 10 - Alexandria VA Film Festival
Beatley Library, 2pm ET
Learn more/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.