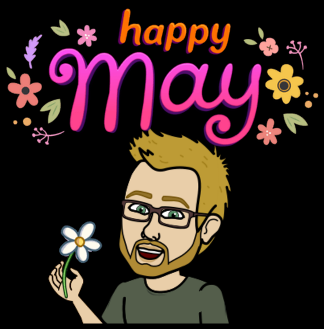
I AM ALS



Get In. We're Ending ALS

What We're Up To

It's finally here – our ALS Awareness Month flag event is happening in Washington, DC NEXT WEEK! We can't wait to see so many of you in person, and we hope those of you at home will join us online. Follow us on Instagram (@iamalsorg) to get notified when our livestream of the speaker series begins around 10:30am on Thursday May 11, and participate on social media by tagging your posts with #ALSinDC and #ALSFreeWorld.

RSVP to the Flag Event

If you haven't yet, please use this form to indicate whether you are attending, whether you'd like to speak at the speaker series, and to sign up for any of our volunteer opportunities!

SIGN UP

COMMUNITY UPDATES

Clinical Trials Team

This team is celebrating the FDA accelerated approval of tofersen (now called Qalsody), a drug that targets SOD1 genetic ALS! Qalsody is now the fourth ALS treatment to be approved by the FDA, the first to receive accelerated approval, and the second treatment approved within the last year. The pace of progress is picking up, and we are so excited to see where we'll go next.

Community Outreach Team

This team is putting on an art show! The show will include a virtual gallery filled with all types of art done by people living with ALS and those who have passed from ALS. There will also be a launch event–stay tuned for details! To submit your art for the show, email ArtistryOfALS@gmail.com. Submissions will remain open until May 15!

Legislative Affairs Team
This team continues to build relationship with members of Congress by thanking them for supporting the #ACT4ALS bill as they advocate for full funding for $75 million for FY 2024. Growing the Senate ALS Caucus is another team priority. Click here to take action to get your Senators to join! https://iamals.org/action/build-the-als-caucus/

Lou Gehrig Day Team
Preparations are in full swing, so step up to the plate and join us for the best Lou Gehrig Day yet! This team along with community members have been planning some amazing activities before, during, and after games. We are looking for team leads for the Philadelphia Phillies, Toronto Blue Jays and Oakland Athletics. Sign up here and get into the games and share your baseball story. https://iamals.org/join-us-for-lou-gehrig-day-2023/

Many Shades of ALS Team
The Many Shades of ALS team is hard at work on their next Let’s Talk About It panel! Each panel focuses on a different topic within the ALS space as it relates to mental health. More details to come!

Veterans Team
These veterans and their allies are advocating for the passage of Elizabeth Dole Home Care Act in the Senate, which has been incorporated into a larger package of Veterans bills aimed at improving access to the VA’s Home and Community-Based Services (HCBS). Help this team out by tweeting at your Senators using this action: https://iamals.org/action/tweet-at-your-senators-to-pass-s-326/. And then email them via this link: https://pva.org/research-resources/pva-action-force/

You know about our newsletters (you’re reading one, after all), but did you know

that we have an email series specifically designed for people who have recently been diagnosed with ALS? Sign up for our Newly Diagnosed Email Series to get four emails over eight weeks, breaking everything you need to know about ALS into manageable pieces. Sign up here: **https://iamals.org/action/sign-up-to-receive-our-newly-diagnosed-email-series/**

Community Spotlight: Kerry Falzone & Plymovent

I AM ALS took one of our first forays into doing ALS outreach and awareness at conferences this past week, and it’s all thanks to Kerry! Kerry works at **Plymovent**, and both parties helped I AM ALS secure a booth at FDIC International 2023, one of North America’s largest firefighter conferences. While there, Kerry, Plymovent, and other ALS advocates (Jill and Cathy to the rescue!) helped us spread awareness of ALS and its heightened prevalence among firefighters, as well as education about how firefighters can better respond to an ALS emergency as first responders. Thank you, Kerry and team!

WHAT'S COMING UP?

NEALS Webinar: Why lumbar puncture and CSF biomarkers are important to ALS therapeutic development

The development of biomarkers for understanding ALS progression and for establishing therapeutic target engagement is at a critical stage. As new therapies are being studied, the identification of specific targets of interest can only be imagined by analyzing the cerebrospinal fluid—a window into the ALS brain. In this webinar on Monday May 8th at 1pm ET, they will discuss the procedure for lumbar puncture and its rationale. A discussion about CSF biomarker development will follow.
Register

Calling All First Responders: Come Learn About ALS

When an emergency strikes, we want you, our first responders, on the scene. But when that emergency involves someone living with ALS, things can be more complicated. The best way to learn about these unique needs is to hear about them from people living with ALS themselves, as well as their caregivers and loved ones. Join the Tim Lowrey Panel Series on May 22nd from 6-7:30pm ET for a panel featuring people living with and impacted by ALS to help grow your knowledge and ensure that you are prepared in case of an emergency involving an individual with ALS!
Register

Hastening the diagnosis of ALS and Muscle cramps in ALS: a new innovative clinical trial with Kampo medicine

This webinar from EverythingALS hosted by Dr. Hiroshi Mitsumoto will focus on two subjects: hastening the diagnosis of ALS, and a new clinical trial studying muscle cramps in ALS. This webinar will take place on May 17th at 7pm ET.
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.**

I AM ALS

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