



Get In. We're Ending ALS

What We're Up To:

Can you believe 2024 is here? And not just that – it's I AM ALS' fifth birthday on Monday, January 22nd, and we can't wait to celebrate with you. While we look back at our accomplishments over the last five years, we are also making some big plans for 2024. Check out this blog post by IAA CEO Andrea Goodman about our priorities for the year, changes to the board of directors leadership, and more:

<https://www.iamals.org/updates/whats-new-in-2024/>

Help us celebrate our birthday!

As critical members of the I AM ALS community, we want you to join the celebration.

Tell us in a post - or better yet, in a video - what I AM ALS means to you! And don't forget to tag us on social media! (@iamalsorg on Twitter and Instagram) Not sure where to start? Check out the example video below.

WATCH
EXAMPLE
VIDEO

COMMUNITY UPDATES



Clinical Trials Team

This team continues to set the bar for clinical trials that are patient-centric. They have released another PaCTD rating for an ALS clinical trial, this

time for Denali Therapeutics (DNL343 - Healey Platform Regimen G). Check out their new rating, as well as ratings for several other ALS clinical trials, here: <https://www.iamals.org/patient-centric-trial-design-pactd-rating-criteria/#dnl343>



Community Outreach Team

In December, this team helped launch the #Fight2EndALS campaign on social media. This campaign pairs actions with powerful, personal videos that we hope will inspire people who know nothing about ALS to act.

Share our latest post, including a video by Juan Reyes, on [Twitter](#), [Facebook](#), [LinkedIn](#) or [Instagram](#). If you'd like to see your story made into one of these videos, head to the F2EA website here:

<https://www.fight2endals.com/>



Legislative Affairs Team

This hardworking team needs your help as they set their 2024 priorities. They are more effective when they meet with legislators on important issues, like increased funding and quicker access to treatments, when they have constituents like you to back them up. Sign up here to become a constituent for your congressional district:

<https://www.iamals.org/action/help-the-legislative-team/>



Lou Gehrig Day Team

This team's newly-created ALS Awareness Library Campaign is off to a great start and they want you to join them! To see how you can partner with local libraries to highlight ALS awareness month this coming May and Lou Gehrig Day on June 2nd, click [here](#).



Many Shades of ALS Team

This team is hosting the next installment of Let's Talk About It: A Mental Health Series this upcoming Monday, January 22nd! The panelists will discuss Travel and ALS – the challenges and rewards of traveling with ALS, guided by their own experiences. Sign up to join them on January 22nd at 5pm ET here: <https://www.iamals.org/action/lets-talk-about-it-travel/>



The Write Stuff

Check out the latest post on The Write Stuff blog by team member The Juan and Only, titled “Jack of All...” here:

<https://www.alsthewritestuff.com/post/jack-of-all> If you'd like to learn more about the ways this team of creative and talented writers plan to

educate others and raise awareness through their writings, check out their team page: <https://iamals.org/action/the-write-stuff-team/>



Veterans Team

Veterans Team co-lead Lara Garey gave [this powerful speech](#) at the Texas Lyceum's quarterly meeting about caregiving and the impact it had on her family. The Elizabeth Dole Home Care Act will improve access to home care for Veterans. Encourage your elected officials to support this bill: <https://www.iamals.org/legislation/elizabeth-dole-home-care-act/>



Youth Lou Gehrig Day Team

Hey all you youth T-ball, little league and softball fans, come join this team as they plan Lou Gehrig Day celebrations throughout the country to raise awareness of ALS and celebrate Lou's legacy. Learn more and sign up: <https://www.iamals.org/action/youth-lou-gehrig-day/>



Your experiences navigating ALS, while sometimes difficult, tedious, or heartbreaking, are also incredibly valuable. If you have ever wondered if sharing your experiences could be helpful to someone else in your shoes, the Peer Support Initiative is for you! Become a mentor and be matched with someone who needs support that only you can provide.

<https://www.surveymonkey.com/r/IAA-Mentor>



In Memoriam: Adam Wilson

We are devastated to share the passing of Adam Wilson. Adam was a foundational member of the I AM ALS volunteer team, and he was instrumental in bringing Lou Gehrig Day to Major League Baseball. He was also a talented musician and a loving father.

He will be deeply missed. Read more about Adam's life and his impact on MLB here:

<https://www.mlb.com/news/lou-gehrig-day-organizer-reds-fan-adam-wilson>

WHAT'S COMING UP?

I AM ALS January Social Hour - January 30th, 4pm ET

The first social hour of 2024 is here! Join your fellow advocates and get to know new people at I AM ALS' monthly social hour. Note: we are starting fresh in 2024 with a new form and a new calendar invite, so even if you signed up in 2023, please be sure to sign up again! After that, you will not need to sign up again in future months.

[Register](#)

National ALS Registry: Learn How You Can Join the Fight Against ALS Webinar - January 25th, 4pm ET

This webinar from the Northeast ALS Consortium (NEALS) will inform and educate people living with ALS and caregivers on the importance of joining and being counted in the CDC's National ALS Registry. This webinar will be hosted by Dr. Paul Mehta, the principal investigator for the registry.

[Register](#)

A conversation with a genetic counselor: Could the ALS in my family be genetic? - January 31st, 12pm CT/1pm ET

This webinar is presented as part of the Les Turner ALS Foundation's ALS Learning Series. Join them for a discussion with genetic counselor Laynie Dratch, ScM CGC, as she describes the role of a genetic counselor and addresses common questions about the genetics of ALS-FTD spectrum disorders, the genetic testing process, and 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.

I AM ALS



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