



Get In. We're Ending ALS

What We're Up To

I AM ALS is hiring! We are currently looking for a Manager of Community Organizing, Chief of Staff, and part-time, freelance Graphic Designer. Check out the listings here: <https://www.iamals.org/jobs/>

Deadline for flags: May 2nd!

There's still time to add your or a loved one's name to a flag for this year's ALS Awareness event. Note: past names are NOT automatically added. If you have submitted a name for past years, you must do so again!

[ADD A NAME](#)

COMMUNITY UPDATES



Community Outreach Team

This team continues to spearhead the #Fight2EndALS campaign on social media by telling moving personal stories of ALS and making them easy to share with elected officials. Check out their most recent creation: Mindy's story, titled "TIME BOMB." <https://www.iamals.org/action/mindys-story/>



Legislative Affairs Team

This team has a goal to secure \$75M of the \$100M for the ACT for ALS Expanded Access Programs and double DOD's CDMRP ALS budget to \$80 M for FY' 25, but they need your help on time-sensitive actions. We need constituents in the following states: AR (district 3), AL (district 4), CA (districts 9, 12, 14 & 62), IL (district 14), LA (districts 4 & 5), MD (districts 2 & 6), NY (district 6), OK (district 5), PA (district 14), and TX (district 6). Click [here](#) to become a constituent or help us recruit anyone you know in these districts!



Lou Gehrig Day Team

This team is partnering with Live Like Lou and the Grayslake Library for an exciting event! "Lunch and Learn: Lou Gehrig and ALS" will offer a crash course to library patrons on Lou Gehrig and the disease that now bears his name. It will take place on May 6th at 12pm CST. Sign up to attend virtually: <https://grayslake.librarycalendar.com/event/lunch-and-learn-lou-gehrig-and-als-31001>

And while you're at it, sign up for another Lou Gehrig event: [Jonathan Eig](#), renowned journalist and author of [Luckiest Man: The Life and Death of Lou Gehrig](#) will be our guest for a virtual author talk on May 1st at 7pm EST. Click [here](#) to sign up, and [here](#) to order your signed copy of the book!



Many Shades of ALS Team

This team needs your help to oppose the EDUCATE bill in Congress. If passed, this bill would cut federal funding to medical schools with diversity, equity and inclusion (DEI) programming, which only worsens existing health disparities and outcomes for populations that already experience them. Learn more about the bill, and contact your Congresspeople to voice your opposition, here: <https://www.iamals.org/action/educate-2024/>



The Write Stuff

This team wants to teach you about the powers of Eyegaze technology! Part One of their series will feature panelists who have done some amazing things using their Eyegaze tech, and it will take place on April 29th at 6:30pm ET. Part Two will focus on the details of Eyegaze functionality and usage, and it will take place on May 13th at 6:30pm ET. Sign up for part one [here](#), and part two [here](#).



Veterans Team

This team wants you to know about a great resource they created to help veterans navigate ALS. Check out [“I’m a Veteran Diagnosed with ALS – Where Do I Begin?”](#) for a master checklist of everything you need to do to ensure you can access the care you need as soon as possible, as well as pages and pages of other tips and tricks.



The Peer Support Initiative is in need of mentors – specifically active caregivers and adult children caregivers. If you are open to sharing your knowledge with another caregiver who is new to ALS, apply to be a mentor:

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

WHAT'S COMING UP?

April Social Hour - April 30th, 4pm ET

This month’s Social Hour will be on April 30th! You know the drill – join your fellow advocates for an hour of no agenda, no goals, no pressure – just fun.

[Register](#)

Navigating Advanced Directives - April 15th, 1pm ET

This webinar will discuss the benefits of advanced directives and what you need to know to make an informed decision. Advanced directives are legal documents that provide instructions for medical care. This webinar is part of the Les Turner ALS Foundation’s ALS Learning Series.

[Register](#)

Constipation in People Living with ALS: Does Autonomic Dysfunction Play A Role? - April 25th, 1pm ET

Join the Northeast ALS Consortium (NEALS) for a session with Dr. Ghazala Hayat, MD, FAAN, FANA, FAANEM. They will delve into the

prevalence and challenges of constipation in people living with ALS and will discuss how constipation might be connected to autonomic system problems in those with ALS, using new research and survey findings.

[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



1200 Pennsylvania Ave NW, #14135 Washington, DC 20044