

I AM ALS



Get In. We're Ending ALS

What We're Up To

Thank you to everyone who made this year's Lou Gehrig Day absolutely incredible! You all hosted over 30 events across the U.S. and Canada, where you handed out flyers, raised awareness, made some noise, and had a great time with your fellow ALS advocates. Whether you organized a meetup, attended one, or cheered us on from home: thank you, thank you, thank you!

We are Here for You

If you are struggling with the impact ALS has had on you or a loved one, we are here to support you. Whether you are living with ALS, are a caregiver, are bereaved, or are otherwise impacted, please check out our ALS support groups.

JOIN A
SUPPORT
GROUP

COMMUNITY UPDATES



Clinical Trials Team

In spite of the FDA's postponement of the PDUFA date for AMX0035, we are still optimistic about the drug's future approval. Check out our tweet thread [here](#) to learn more about what we hope for the future, and share it!

Community Outreach Team



You already get this newsletter – you’re reading it, after all – but this team wants to get more eyes on I AM ALS’ emails! Please share [this post](#) and encourage your friends to sign up for our newsletter.



Familial ALS Team

This team has been hard at work creating some great content to fill gaps in the familial/genetic ALS literature. Check out Jean Swidler’s piece on participating in ALS research [here](#).



Many Shades of ALS Team

This team has an amazing Ask Me Anything ALS virtual event next week! The topic is “Addressing ALS Communication Challenges.” Bring your questions and your listening ears – the team will share community-created communication solutions, how to navigate tough conversations about ALS, and some of their favorite technology for communicating. Sign up to join them [here](#).



Thank You Squad

This team wrote over 600 thank you notes in the past couple of weeks for Lou Gehrig Day donations alone, and they’re not stopping now! If you know a Squad member, send them a thank-you note of your own!



Veterans Team

This team would love your help making sure the Justice for ALS Veterans Act gets passed in Congress. Use the form [here](#) to write to your Congresspeople and ask them to make the Justice for ALS Veterans Act a priority.



In Memoriam: Zamir Kociaj

It is with deep sadness that we share the passing of Zamir Kociaj. Zamir is remembered in the ALS community as an amazing storyteller, as well as a loving father and husband. Even in the face of ALS, he was unfailingly kind. He, and his smile, will be sorely missed. Read his story in his own words [here](#) and his

WHAT'S COMING UP?

Ask Me Anything ALS - Addressing ALS Communication Challenges

People living with ALS and their loved ones have found solutions to the communication disruptions that often come with ALS. They continue to have tough conversations about their diagnosis and educate people on how to communicate with them. Bring your questions and join the Many Shades of ALS team on June 15th at 6 p.m. ET.

[Register](#)

An Overview of Medicare for People Living With ALS

This webinar is part of the Les Turner ALS Foundation's ALS Learning Series. This presentation on June 23 at 1 p.m. ET will examine Medicare eligibility, enrollment, coverage, costs, assistance paying for costs, and considerations when choosing between traditional Medicare and a private Medicare advantage plan. Questions, answers, and discussion will follow the program.

[Register](#)

A Conversation with Dr. Adam Russell on the Vision for ARPA-H

The Advanced Research Projects Agency for Health (ARPA-H) is a new, proposed division that will equitably benefit the health of all Americans by catalyzing health breakthroughs. To learn more about ARPA-H, the HHS Office of Intergovernmental and External Affairs (IEA) invites you to a discussion with ARPA-H Acting Deputy Director Dr. Adam Russell. The conversation will focus on the goals of the agency, the vision for its future, and opportunities to get engaged in ARPA-H's groundbreaking work and will be moderated by IEA Director Marvin Figueroa.

[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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