



hey.

# Get In. We're Ending ALS

## What We're Up To

We lost so many incredible people to ALS in 2023. The Community Outreach Team had the amazing idea to honor these folks with an In Memoriam video in 2022, and this has now become an annual tradition. The 2023 In Memoriam video is now available. We hope you will join us in honoring the memory of these incredible people.

<https://www.youtube.com/watch?v=JKB8je-SFto>

## Register for the ALS Community Summit!

In case you missed it: our flag event and community summit will be in DC from May 29th - June 1st! Get all the info you need on our [landing page](#), and take the following actions:

SIGN UP

ADD A FLAG

## COMMUNITY UPDATES



### Clinical Trials Team

This team has granted a rare 5-star PaCTD rating to an ALS clinical trial – Ionis' Ulefnersen! A 5-star rating indicates a high standard of patient-friendliness and humaneness in the trial. Check out the full score [here](#), and learn more about PaCTD and see other ratings:

<https://www.iamals.org/patient-centric-trial-design-pactd-rating->

[criteria/](#)



### Community Outreach Team

The Community Outreach Team is working hard to reach their goal of hosting 56 Tim Lowrey Panels this year. That's DOUBLE the number of panels they provided last year! Help them reach the goal: if you or someone you know could benefit from an educational presentation about ALS from people with lived experience, you can request a panel here:

<https://www.iamals.org/action/request-a-panel/>



### Legislative Affairs Team

It's all hands on deck for this hard-working team whose #1 priority is securing \$75M of the \$100M for the ACT for ALS Expanded Access Programs and doubling CDMRP funding to \$80 M for FY' 25. Click [here](#) to become a constituent and support letter writing efforts – or better yet, join the team and help their efforts:

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



### Lou Gehrig Day Team

The Lou Gehrig Day Team is adding to their roster, so step up to the plate and join them as they plan for the best Lou Gehrig Day yet! We welcome new members as well as Stadium Co-leads for the following teams: Chicago Cubs, Oakland Athletics, San Diego Padres, Texas Rangers, Atlanta Braves, Milwaukee Brewers, Arizona Diamondbacks, Colorado Rockies, LA Dodgers, Miami Marlins, Toronto Blue Jays, Chicago White Sox, and Kansas City Royals. Learn more and join the team:

<https://www.iamals.org/action/lou-gehrig-day-team/>



### The Write Stuff Team

The Write Stuff Team is busy developing their visiting writers series so that their members can hear others share about their craft! The team was recently visited by [Nate Methot](#), author of *A Life Derailed: My Journey with ALS* and will be visited next week by poet and disability activist [Ekiwah Adler-Beléndez](#). Join the team to connect with more writers and celebrate a shared love of writing! [https://www.iamals.org/action/the-](https://www.iamals.org/action/the-write-stuff-team/)

[write-stuff-team/](https://www.iamals.org/action/the-write-stuff-team/)



### Veterans Team

Did you know there's an I AM ALS support group for veterans living with ALS? They meet on the fourth Wednesday of every month at 1pm ET to share their experiences and receive emotional support. Sign up for the

Veterans Support Group: <https://www.iamals.org/action/join-a-support-group/>



### Youth Lou Gehrig Day Team

Spring is in the air and youth leagues are getting ready to play ball! Now is the time to join the team and raise awareness about ALS and Lou Gehrig's legacy with kids across the country. Get your youth league involved or join the team: <https://iamals.org/action/youth-lou-gehrig-day/>

### In the News

On Rare Disease Day 2024, Secretary Buttigieg announced a **proposed rule** that would be the biggest expansion of rights for passengers who use wheelchairs since 2008. In addition, The Advanced Research Projects Agency for Health (ARPA-H) provided a \$48.3 million **grant to Every Cure**, a nonprofit on a mission to save lives by repurposing existing medicines.



When you or a loved one are first diagnosed with ALS, there is so much information to learn, it can be overwhelming. Our Newly Diagnosed Email Series aims to deliver this information in a digestible way, with a total of four emails delivered to your inbox over eight weeks. Sign up for the Newly Diagnosed Email Series here: <https://www.iamals.org/action/sign-up-to-receive-our-newly-diagnosed-email-series/>



## **In Memoriam: Garrett Smith**

We are deeply saddened to share the passing of Garrett Smith. Garrett was a Veteran of the US Navy and was deeply passionate about Veterans issues within the ALS landscape; he advocated for better care within the VA and helped create resources as part of the Veterans Team. He is survived by a large and loving family, including his wife, children, and grandchildren. He will be sorely missed. Read Garrett's story in his own words [here](#), and his obituary [here](#).

## **WHAT'S COMING UP?**

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### **ALS Genetics: Lessons from familial ALS/FTD and progress towards ALS prevention - March 6th, 7pm ET**

This webinar from Everything ALS will be hosted by Dr. Mark Garret. Dr. Garret's academic pursuits have led to presentations on cutting-edge research, particularly in the realm of advancements in treatments for familial ALS and pre-symptomatic therapies for neurodegenerative diseases.

[Register](#)

### **Rare Neurodegenerative Disease Efforts Under the ACT for ALS - March 8th, 12pm ET**

This hybrid meeting will provide an opportunity to share the 2024 priorities for Critical Path for Rare Neurodegenerative Diseases (CP-RND) program to provide an update on efforts from the Food and Drug Administration (FDA) and National Institutes of Health (NIH) focused on rare neurodegenerative diseases.

[Register](#)

### **The Science Behind ALS Treatments: Riluzole, Radicava, and Relyvrio - March 18th, 4:30pm ET**

This webinar from NEALS is for both clinicians and people living with ALS and will review the 3 drugs that are currently FDA-approved in the United

States for the general ALS population. Panelists will present information on Riluzole, Radicava, and Relyvrio, including drug mechanism, findings from clinical trials, and potential benefits, risks, and costs.

[Register](#)

### **IN CASE YOU MISSED IT: Hilarity for Charity's CareCon 2024: Love and Dementia Panel**

I AM ALS co-founder Sandra Abrevaya was a panelist on the Love and Dementia Panel at this year's CareCon! You can watch the full recording of the panel here: [https://www.youtube.com/watch?v=PLtfco-EH1M&list=PLg3pcgWyEPY\\_nEljwGG56YeDulzLK14bh&index=4](https://www.youtube.com/watch?v=PLtfco-EH1M&list=PLg3pcgWyEPY_nEljwGG56YeDulzLK14bh&index=4)

[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](http://iamals.org).

**I AM ALS**



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