



# Get In. We're Ending ALS

NOTE: I AM ALS will be closed for winter break from December 24th - January 2nd. We will be back on January 3rd!

## What We're Up To:

We are thrilled that the 117th Congress passed the Omnibus spending bill, which has allocated \$75 million in funding in FY2023 for the Expanded Access Programs (EAPs) outlined by ACT for ALS. This would not have been possible without the incredible and tenacious advocates in the ALS community. The future of ALS is just a little brighter, and we cannot thank you enough. We can't wait to see what we will continue to accomplish in 2023!

## Seeking mothers of people living with ALS

The Peer Support Initiative is in need of mothers of people living with ALS to serve as mentors. Apply below!

[LEARN MORE AND APPLY](#)

## COMMUNITY UPDATES



### Clinical Trials Team

This team has been hard at work making sure ALS Signal is up to date with new trials and observational studies. Check it out [here](#) and share it far and wide.



### Community Outreach Team

This team spearheaded a multi-team initiative to honor veterans we've lost to ALS at this year's Wreaths Across America event last weekend.

You can see photos from the Indiana team [here](#), and the New York team [here](#).



### Legislative Affairs Team

Co-chair Becky Mourey spoke with Matthew Perrone of the Associated Press about Relyvrio's approval, its high price, and the battle many people living with ALS are having to wage to get it covered by their insurance companies. Read the article [here](#).



### Lou Gehrig Day Team

This team is entering its second month of life, so they are recruiting members! If you'd like to be part of the planning committee for 2023's Lou Gehrig Day, join the team [here](#).



### Thank You Squad

We just wanted to say a huge THANK YOU to this team for all their hard work this year! Stay tuned in 2023 for the final tally of how many handwritten notes they sent out in 2022. (Hint: it's in the thousands!)



### Veterans Team

Co-chair Shelly Hoover is also in the news this week on the Relyvrio front. Shelly and her husband (and fellow team member) Steve Hoover spoke to BioPharma Dive about their struggle to access Relyvrio through the VA. Read the article [here](#).



The holidays can be a time of love and togetherness, and they can also be stressful. Don't be afraid to ask for help and communicate what you need. Not sure how someone can help? Share this [Instagram post](#) outlining how others can help people impacted by ALS!



### In Memoriam: Carl Polo

We are deeply saddened to share the passing of Carl Polo. Carl's daughter Gia came to I AM ALS when her dad was first diagnosed, and we are honored that she shared his life and their journey with us.

Carl will be missed by so many. Read Gia's story about her dad [here](#), and his obituary [here](#).



### **In Memoriam: John Wilkinson**

We are also heartbroken to announce the passing of John Wilkinson. John was a regular at Social Hour, where he made many friends who miss him terribly. He loved sports of all kinds – he was a strong athlete, and an even bigger O.U. fan. John's kindness and humor will be sorely missed. Read his obituary [here](#).

## WHAT'S COMING UP?

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### **I AM ALS Social Hour**

Social Hour is moving from weekly to monthly, and January's social hour will be on January 10th from 4 - 5pm ET. Join us for an hour of unstructured, agenda-less time to get to know your fellow advocates.

[Register](#)

### **Pat's Maps**

All-star advocate Pat Dolan has been bringing us his incredible geospatial maps for years now, and now he's giving us a crash-course! Join Pat for a tour and explanation of the Geospatial Hub and some of his favorite maps on January 19th at 4pm ET. In the spirit of mapping, we hope you find your way there!

[Register](#)

### **Instagram 101**

Twitter 101 was so successful that we're taking on Instagram! Join Self-Taught Social Media Mama Mandi Bailey and Discreet Marketing Pro Kerry Falzone for a crash-course in how to utilize Instagram for advocacy on January 26th at 5pm 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](http://iamals.org).

I AM ALS



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