



# Get In. We're Ending ALS

NOTE: I AM ALS will be closed in observance of Independence Day from July 4 - July 8.

This week brought us two big wins for ALS research funding! First, the House Defense Appropriations Committee allocated \$40 million for ALS research in FY2023 through the Department of Defense's CDMRP program. Then, the House Labor HHS Appropriations Committee allocated \$75 million for ACT for ALS to support expanded access for ALS clinical trials through NIH! This could not have happened without tireless advocacy from the ALS community.

## 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

Last week, this team met with a drug sponsor that currently has an active clinical trial with the potential to be effective against ALS. The team continues to be a trusted source for ethics and efficacy in clinical trials.



### Community Outreach Team

As always, this team is spreading awareness and knowledge about ALS, and they need your help to do it! You can help them by sharing **this “What is ALS?” video** to anyone who might not be familiar with the disease. Knowing is the first step to changing things for the better!



### Familial ALS Team

Team member Tucker Olson recently put together a beautiful story that chronicles his family’s generations-long journey with SOD1 genetic ALS. Read about Tucker and his family **here**.



### Legislative Affairs Team

This team is leading a campaign on social media to thank ALS champions in Congress that made this appropriations funding possible. Join them by tweeting at your favorite ALS champion, or by retweeting our tweet **here**.



### **Community Spotlight: Mark Purvis**

Mark is a new member of the **Community Outreach Team** who came in strong with ideas and passion. He cared for his best friend David after his ALS diagnosis until he passed away in 2021. Read Mark’s story of their remarkable friendship **here**.

## WHAT'S COMING UP?

### **Webinar: Why patient centricity is no longer optional in ALS clinical trials**

This webinar will cover the need for patient involvement in ALS clinical trials in order to improve recruitment, retention and data quality, as well as readiness to adhere to impending regulatory changes. Join Paul Wicks, Ph.D., a neuropsychologist, independent consultant and

Sano Genetics investor and Cathy Collet, a world-leading ALS advocate, for an important discussion on June 30th at 11 a.m. ET.

[Register](#)

### **ALS at All Ages**

EverythingALS is hosting this webinar in conjunction with members of Her ALS Story to show that ALS can strike anyone at any age. Her ALS Story is made up of women who were diagnosed with ALS before age 35. This will take place on Zoom on July 20th at 4 p.m. PT.

[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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