



# Get In. We're Ending ALS

## What We're Up To:

2023 was a big year for ALS advocacy: from FDA approval of Qalsody, to three substantial EAP grants doled out because of ACT for ALS, to roaring support for several pieces of crucial legislation, to [No Ordinary Campaign](#) hitting the big screen, this community has moved mountains! As we strive toward even bigger goals for 2024, we want to take a moment to recognize the incredible accomplishments of the I AM ALS community teams. We hope you'll take this opportunity to admire their hard work and maybe consider joining their ranks in 2024.

## While we have you...

Actor Jason Kravits is performing his comedy show, *Off the Top*, on December 21st, and you can watch the livestream from anywhere! Ticket proceeds will benefit I AM ALS.

[LEARN MORE  
& GET  
TICKETS](#)

## COMMUNITY TEAMS: 2023 in Review



### Clinical Trials Team

This year, the Clinical Trials team reevaluated the [Patient-Centric Trial Design \(PaCTD\) Rating Criteria](#) and rated ALS Clinical trials under this revised rubric. They also updated and created an automated updating system for [ALS Signal](#). They dramatically accelerated their outreach to drug sponsors to encourage them to follow the [PaCTD Rating Criteria](#) when designing their trials. The team is incredibly proud to have successfully pushed more ALS drug sponsors to include Open Label

Extensions and Expanded Access Programs in their clinical trial designs.



### Community Outreach Team

Through the [Tim Lowrey Panel Series](#), ALS advocates reached over 800 medical professionals and students through 28 presentations. This is an incredible program that can and will continue to grow – join the [team](#) to help make these panels happen! This group also helped launch the [Keep Swinging campaign](#) in partnership with [Boge Golf](#), in honor of the late John C. Whigham. They have raised over \$80,000 for I AM ALS to date, and their Keep Swinging campaign brought ALS awareness in a new, fun way.

Later in the year, a group of incredible ALS advocates created the #Fight2EndALS campaign to capture [stories from real people](#) living with and impacted by ALS in the hopes of spreading awareness and inspiring action. Have a story you'd like to submit to be turned into a video? You can do so [here](#)!

Last but not least, advocates from this team also created a [virtual art gallery](#) filled with art done by people living with ALS. They also did [exclusive interviews](#) with some of the artists, and hosted an [Artists Panel](#).



### Familial ALS Team

This team revamped their programming with the helpful vision of two new co-chairs in 2023, and they made some big waves, hosting three familial ALS-centric events over the course of just a few months. You can watch the recordings of all of them on our YouTube channel:

- [What's in a Gene? Introduction to Familial ALS](#)
- [Big Feelings in Familial ALS: A Community Conversation about Generational Trauma](#)
- [Ask Me Anything ALS: Genetic Testing](#)



### Legislative Affairs Team

This team put in a giant effort to secure funding for the ACT for ALS this year, and they did it! \$75 million was granted for expanded access programs (EAPs) for people who do not qualify for clinical trials, and \$25 million was granted for research.

The team has also been advocating for The Promising Pathway Act (PPA)

and has helped gain congressional support for it, with 18 Cosponsors In the Senate and 9 in the House. Click [here](#) to contact your congresspeople about the Promising Pathway Act.

None of this would be possible without the help of a large pool of constituents who volunteer their names and addresses to be used to contact their legislators about important ALS policies. But such a large pool of constituents also wouldn't exist if it wasn't for Legislative Affairs Team members, who spent countless hours reaching out to potential advocates. They currently have constituents in 233 of the 435 congressional districts. Help close this gap by signing up or sharing [this page](#).



### **Lou Gehrig Day Team**

This hardworking team facilitated pregame and game-time activities designed to connect the community and raise awareness for ALS in 25 MLB stadiums this year! They expanded from what was once a seasonal team to a team that meets year-round. They have built relationships with other ALS organizations and are creating additional ALS awareness campaigns to make Lou Gehrig Day 2024 the best one yet! Everyone is welcome to step up to the plate and join the team [here](#).



### **Many Shades of ALS Team**

This team hosted several installments of their critically important mental health series, Let's Talk About It, in 2023. You can watch recordings of two of them on YouTube: [Coping with Loss of Function/Independence](#), and [Navigating the Holidays with ALS](#). They have continued their work toward building a better ALS landscape for people of color and marginalized groups.



### **Thank You Squad**

This team has written over 2,300 handwritten thank you notes to donors to I AM ALS in 2023 alone! Their dedication (and penmanship) knows no match – they know just how to make each donor feel seen and appreciated. Thank you, Thank You Squad!



### **The Write Stuff**

This team launched in February with the mission to create a warm and welcoming space for storytellers of any experience level or ability to share ALS stories through writing. The group was founded with the intent of educating others and raising awareness of ALS, both within and outside of

the ALS community. They created [The Write Stuff](#) Blog in July, which now boasts over 60 members, 17 blog posts and 18 forum discussions. They also hosted their inaugural [Literary Salon](#) on October 2nd, where team members read their personal writings. Click [here](#) to learn more or join this creative team.



### Veterans Team

This year, this team established a relationship with the office of the Secretary of Veterans Healthcare, which opened direct channels of communication to address challenges faced by Veterans with ALS. They also presented at the annual PVA Healthcare Summit for the second time. The title of their presentation was “Impact of Volunteers in Improving Support for Veterans with ALS.”

Team members also appeared on the [Overwatch Collective’s podcast](#) to help raise ALS awareness and competency among the podcast’s audience, which is primarily first responders.



### Youth Lou Gehrig Day Team

This team first came together in 2023, and they partnered with four Little Leagues in Vienna, Virginia and the Chicagoland area to celebrate Lou Gehrig Day, share Lou’s legacy, and highlight ALS awareness to over 4,500 kids and their families. They distributed 3,000 I AM ALS gummy bracelets, gave pregame dugout speeches, and provided visibility to people living with ALS and their loved ones. Click [here](#) to join this expanding team!



I AM ALS’ Community Support Team wants to take a moment to thank the peer mentors, peer mentees, and support group attendees that make their programs incredible. Click on these links to learn more about our [Peer Mentorship Program](#) or [Support Groups](#).

To all the volunteers, supporters, cheerleaders and contributors who helped make 2023 one for the books: THANK YOU. We could not do what we do without you. We send you our warmest wishes for the holiday season and can't wait to make more good trouble with you in 2024.

With hope,  
I AM ALS



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](https://iamals.org).

I AM ALS



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