



# Get In. We're Ending ALS

## What We're Up To

The FDA's Advisory Committee meeting regarding NurOwn is drawing ever closer (September 27th), and the period for public comment is now open. We've created a guide that will help you write and submit testimony and make it the best it can be. Check it out here:

<https://iamals.org/updates/guide-to-submitting-written-testimony-to-the-fda-about-nuown/>. Note: the comment period will close on September 20th.

## Now recruiting peer mentors!

We are looking for some amazing **people living with ALS** to serve as mentors to others in similar situations. If you would like to be a mentor, please apply!

[APPLY HERE](#)

## COMMUNITY UPDATES



### Clinical Trials Team

This team is focused on equitable trial and treatment access, which is why they're especially concerned about cases of people being denied access to Relyvrio. If you have been denied access to Relyvrio for any reason, please let us know: <https://iamals.org/action/denied-access-to-relyvrio/>



### Familial ALS Team

This team is bringing you the next installment of the Ask Me Anything ALS series! This one will be focused on genetic testing for ALS. Panelists

include individuals who have and have not been tested, those with familial and sporadic ALS, as well as a genetic counselor. This event is coming up on August 29th, so be sure to sign up (and ask your questions in advance): <https://iamals.org/action/ask-me-anything-als-genetic-testing/>



### **Legislative Affairs Team**

Thanks in part to this incredible team - led by the amazing Glen Rouse, Jack Silva, Nicole Cimbura, and Troy Fields - the \$75 million for the ACT for ALS funding has passed in the House and Senate and will move on to the committee process! And while that is awesome, they're not taking a break. You can help them on their next endeavor: building the ALS Caucus! Learn how you can help: <https://iamals.org/action/build-the-als-caucus/>



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

This team is psyched for their next Let's Talk About It event, which is coming up NEXT WEEK! Join the team on August 7th at 6pm ET as they discuss how they cope with the ever-changing reality that is ALS. Participants will share their personal experiences with losing function and independence and how they face these challenges. Sign up to join: <https://iamals.org/action/lets-talk-about-it-august/>



### **The Write Stuff**

The Write Stuff Team now has a blog! Read the first two blog posts, [\*\*Sticks and Stones\*\*](#) by Dr. Shelly Hoover and [\*\*Dear ALS\*\*](#) by the Juan and Only, and meet the Write Stuff team here: <https://www.alsthewritestuff.com/>



### **Veterans Team**

This team is working hard to make sure Justice for ALS Veterans gets passed in Congress. You can help them make this happen by sending pre-populated emails to your state representatives: <https://iamals.org/action/justice-for-als-veterans-2023/>

**New resource alert! Last year, we asked the ALS community on social media for the best ways to offer help to someone**

## COMMUNITY SUPPORT CORNER

impacted by ALS. And, gosh, did they deliver! Check out this amazing resource with lots of ideas for how to help someone living with ALS, their caregivers, or their family in a variety of situations: <https://iamals.org/get-help/ways-to-offer-help-to-people-impacted-by-als/>



**Community Spotlight: Chad Klinck**  
Meet Chad! After taking some time to cope with this life-altering diagnosis in 2020, Chad decided he wanted to give back and make a difference for people living with ALS. His four amazing kids and girlfriend Adrienne give him the strength and inspiration to keep moving forward as a successful fundraiser. Read more about Chad's ALS journey and current fundraising goals: <https://iamals.org/chad-klinck-fundraiser/>

# WHAT'S UP? COMING

## **Accelerating Treatments and Improving Quality of Life: Workshop 1**

This webinar series from the National Academies of Sciences, Engineering and Medicine (NASEM) hopes to examine key actions the public, private, and nonprofit sectors should take to make ALS a livable disease within the next decade. This first workshop on August 10 will consider the type/range of care and services people with ALS and their families need, and how to ensure they receive that care.

[Register](#)

## Webinar on gene-environment interactions leading to ALS

This webinar from EverythingALS will feature Jonathan Cooper-Knock, M.D. Ph.D, whose lab is focused on discovering gene-environment interactions which modify the risk and severity of ALS. The hope is that this could provide personalized interventions for ALS patients and their families. Join them on August 9th at 7pm ET to learn more about this research.

[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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