

# Get In. We're Ending ALS

## What We're Up To

The last few months have been busy! Between the #ALSinDC flag event, Lou Gehrig Day, and everything in between, this community accomplished so much. We have been reflecting on ALS Awareness Month 2023 and the #ALSinDC flag event, and want to share everything we learned. You can check out our full recap deck [here](#), which includes feedback from those who attended and ideas for future years.

Also, Cigna is still denying people access to Relyvrio, one of the few approved treatments for ALS. Help us put a stop to this by tweeting at Cigna using [this action](#).

## Check in with Andrea!

I AM ALS CEO Andrea Goodman hit the ground running when she joined I AM ALS in April. Now, 100 days(ish) in, she's reflecting on what she's learned and is looking forward to the next 100 days and beyond.

[READ THE BLOG POST](#)

## COMMUNITY UPDATES



### Clinical Trials Team

This team constantly strives to make sure ALS Signal is up to date with the latest clinical trials and observational studies from around the world. Check it out and share it so the world knows where to look!

<https://iamals.org/get-help/als-signal-clinical-research-dashboard/>



### Community Outreach Team

This team is hard at work finding audiences for their Tim Lowrey panels, which feature panelists living with and impacted by ALS and aim to teach others about the realities of ALS. You can request a panel for your audience of choice here: <https://iamals.org/action/request-a-panel/>



### Lou Gehrig Day Team

We hit it out of the park with Lou Gehrig Day 2023 and this hard working team is already making plans for 2024! So get in on the early planning and step up to the plate and join this awesome team:

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



### Legislative Affairs Team

Our relentless advocates continue to connect with members of congress to secure the 75 million funding for ACT for ALS programs for FY2024. They are also supporting the Justice for Veterans Act by reaching out to members of the Senate. You can help the legislative team build relationships with your representative and secure ALS funding by filling out this form: <https://iamals.org/action/help-the-legislative-team/>



### The Write Stuff

This new team of writers have set their goals and are putting pen to paper as they raise awareness through increased sharing of personal and organizational stories through a variety of media and platforms. Email Deb at [deb@iamals.org](mailto:deb@iamals.org) to learn more or join the team here:

<https://iamals.org/action/the-write-stuff-team/>



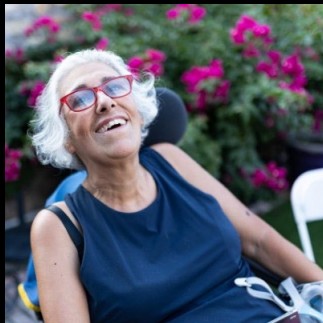
### Veterans Team

These Veterans need your help to support the The Justice for ALS Veterans Act. This legislation will extend increased Dependency and Indemnity Compensation (DIC) paid to surviving spouses of veterans who die from ALS, regardless of how long the veterans lived with ALS. Use this action to send a letter to your Senators, asking them to support the Justice for ALS Veterans Act: <https://iamals.org/action/justice-for-als-veterans-2023/>

Our Online Resource Center has tons of information to help you navigate every aspect of ALS, but did you know it also



has a local resource finder? There are so many resources available locally, beyond just ALS clinics. Discover ALS resources and filter by state here: <https://iamals.org/connect/>



### **In Memoriam: Julie Suarez**

We are devastated to share the passing of Julie Suarez. Julie brought warmth and laughter wherever she went, and she never hesitated to help someone in need. She was open about her ALS journey, sharing hard truths and helpful tips with anyone who asked. She had a massive network of people who loved her, including many at I AM ALS. She will be dearly missed. Read Julie's story in her own words:

<https://iamals.org/stories/julie-suarez/>



### **In Memoriam: Ryan May**

We are also incredibly sad to share the passing of Ryan May. Ryan was kind, passionate, and brilliantly smart – he studied law and he had a ravenous appetite for politics. He brought this appetite (and his brother Garrett) to the Legislative Affairs Team, where they fought for change together week after week. Ryan passed away in June at the age of 26,

and is survived by his wife Rachel and young daughter Molly. Read more about Ryan in his obituary:

<https://www.premierfuneral.com/obituaries/Ryan-May/>



### **In Memoriam: Seth Poling**

We are also heartbroken to share the passing of Seth Poling. Seth was an amazing husband, father, friend, and person. He was completely devoted to his wife Erika and their two sons, Liam and Bayler. He shared the good, the bad, and the ugly of ALS on social media and through **his blog**, and he kept his sense of humor and winning smile through it all. He will be sorely missed. Read Seth's story in his own words:

<https://iamals.org/stories/cory-seth-poling/>

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

---

### **2nd Annual I AM ALS Talent Show**

That's right – it's back! We loved seeing your hidden talents so much last year that we're having another talent show! Join us on July 28th at 6pm ET to see even more of your fellow advocates show off their amazing talents. (Note: you can perform in the show too! But we understand if you'd rather just watch.)

**[Register](#)**

### **NANDSC Fundamental Neuroscience Working Group (FNWG) Public Webinar**

During this webinar open to the public, the FNWG will present draft recommendations to optimize or enhance current NINDS (National Institute of Neurological Disorders and Stroke) programs in support of the FN research mission and receive public input on the proposed draft

recommendations through a Q&A session. Join in on July 27th at 12pm ET.

[Register](#)

### **How an iPhone Can Become the Ultimate ALS Communication and Assistive Tool**

This webinar from Compassionate Care ALS (CCALS) will feature tech entrepreneur Tom Meadows as he unveils his step by step toolkit for unlocking existing iPhone capabilities that will “allow anyone with ALS, or other neuro-degenerative condition, to navigate the changing communication needs they may have along the path of their disease.” Join in on July 30th at 1pm 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



1200 Pennsylvania Ave NW, #14135 Washington, DC 20044

