# IAM ALS



# Get In. We're Ending ALS

#### What We're Up To

I AM ALS co-founders Brian Wallach and Sandra Abrevaya were honored to receive the Harvey and Bonny Gaffen Advancements in ALS Award at the annual Les Turner Hope Through Caring gala! Brian and Sandra gave a lovely acceptance speech, preceded by our friend and ALS champion Rep. Mike Quigley. If you're ready to be inspired, watch the video <u>here</u>.

### Tell Cigna: Cover Relyvrio!

Cigna health insurance decided to no longer cover Relyvrio, an FDA-approved treatment for ALS. Help the community reverse this decision by tweeting at Cigna with this form.

> TWEET AT CIGNA

## **COMMUNITY UPDATES**



#### **Clinical Trials Team**

This team wants to see you at Ask Me Anything ALS - Clinical Trials! Members of this team will be ready and able to take your questions about identifying and preparing for a clinical trial, what to expect when participating in a trial, and more. Sign up **here** to join us on February 28th at 6pm ET!



#### **Community Outreach Team**

This team is getting excited for the launch of the Keep Swinging Campaign on March 1! This campaign brings awareness to ALS, highlights the experiences of people who have been impacted by ALS, raises funds to keep the movement going, and shows how people living with and impacted by ALS adapt to challenges. It will feature stories of real people living with and impacted by ALS, Boge merchandise cobranded with I AM ALS to raise money for the cause, and a new ALS social media challenge. Check it out and show us your swing to #Swing4ALS!



#### Familial ALS Team

This team wants you to know about the upcoming Advisory Committee (AdCom) meeting about Tofersen. Tofersen is a safe, effective drug that treats SOD1 ALS, a particularly aggressive form of familial/genetic ALS. Learn more about Tofersen, the AdCom, and how you can submit comments to the FDA <u>here</u>.



#### Legislative Affairs Team

Over the next few weeks, this team's top priorities will be securing funding for ACT for ALS for FY2024 and building the ALS Caucus. You can help the legislative team build relationships with your elected officials and secure ALS funding by filling out <u>this form</u>.



#### Lou Gehrig Day Team

MLB Spring Training has begun, which means Lou Gehrig Day will be here before we know it! So step up to the plate and join this awesome team as they plan pre-game, game time and post-game activities for major, minor, little, and recreational leagues all over the country. Learn more and join the team <u>here</u>.



#### The Write Stuff

What's that? Another new team?? You've got that right! This new team of writers are just getting started and are currently creating their mission statement and goals. Email Deb Paust at <u>deb@iamals.org</u> to learn more or join the team.



#### Veterans Team

Team co-chair Shelly Hoover is in the news again, this time at Military Families Magazine! In this piece, Shelly is her usual charming self, while also driving home important points about the connections between ALS and military service. You can read the whole article (and see some glamor shots of Shelly) here.



The benefits of support groups are clear: they provide a space to talk openly about your experiences and feelings and can help you feel less isolated, especially when you meet others with similar experiences. With that in mind, I AM ALS now has a support group specifically for Veterans living with ALS. They meet on the fourth Wednesday of every month from 1-2pm EST. Learn more and sign up <u>here</u>.

### In Memoriam: Becky Mourey

We are heartbroken to share the passing of Becky Mourey. Becky led with firm kindness and would not back down from what she knew was right. She was tireless in her pursuit of a better world for those living with ALS. While this movement will not be the same without her, it has also been forever changed and shaped by her. Read more about Becky's incredible life in her obituary <u>here</u>.



## WHAT'S COMING UP?

#### **February Social Hour**

For those who may not know, social hour is an hour-long meeting where members of the community can come to hang out, chat, and spend time together. We know that the ALS community works hard to advocate for better lives for people living with and impacted by ALS. But we also know that part of being an effective advocate is building relationships and taking time to take care of yourself. Social hour makes space for the community to do just that. Join us on February 28th at 4pm ET for this month's gathering! **Register** 

#### Ask Me Anything ALS - Clinical Trials

While there are currently no cures for ALS, there are numerous clinical trials taking place right now across the country with the goal of finding safe and effective therapies. With so many opportunities available, finding the right fit and participating in a clinical trial can be overwhelming and confusing. We hope you will join us on February 28th at 6pm ET for a conversation that will help answer some of your burning questions about clinical trials.

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.



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