# IAM ALS



# Get In. We're Ending ALS

#### What We're Up To

We are gathering signatures on a petition urging the FDA to hold an Advisory Committee meeting for NurOwn, an experimental ALS treatment. An Advisory Committee meeting (or AdComm) will convene a panel of experts to examine NurOwn's trial data and will give others in the ALS community a chance to share their direct experiences with the treatment.

# **Sign the Petition**

Help us reach our goal of 15,000 signatures before December 8th! Sign the petition and SHARE with your networks.

SIGN HERE

# **COMMUNITY UPDATES**



#### **Clinical Trials Team**

Do you want to meet directly with trial designers and have input on making trials more patient-friendly? Get into the nitty gritty of drug efficacy? Meet like-minded individuals with a penchant for cutting through red tape? Then join the Clinical Trials Team! You can learn more about what they're up to and sign up to join them <a href="here">here</a>.



#### **Community Outreach Team**

The ALS community has shouldered a lot of loss this year. The Community Outreach Team had a wonderful idea to honor those we have lost in 2022 by creating an In Memoriam video. If your loved one passed

away from ALS during 2022 and you would like them included in the video, please fill out **this form**.



#### **Lou Gehrig Day Team**

New team just dropped!! The Lou Gehrig Day Team will – you guessed it – help plan and execute Lou Gehrig Day events for future years. They're gathering members, so if you're interested, please sign up to join them here!



#### Many Shades of ALS Team

Katrina Byrd, co-chair of this amazing team, attended the 2022 STAT Summit a few weeks ago and brought down the house with a beautiful, moving speech. You can watch it <a href="here">here</a>, and let us know if you cry (we certainly did).



#### **Veterans Team**

This team, in close collaboration with other veterans living with ALS, released a press release this week in support of BrainStorm's request for the FDA to hold an AdComm for NurOwn. Read the full release here.



Ask Me Anything ALS - Finding Meaning as a Caregiver is coming up next week on Tuesday, December 6 at 6:00pm ET! Join us as we discuss how current and former caregivers and loved ones to people living with ALS have coped with the mental and emotional reactions to an ALS diagnosis, the exhaustion that often accompanies it, and how they prioritized finding meaning and purpose through and beyond ALS. Register for this event here, and watch the recording of Finding Meaning as a Person Living with ALS here. This event will be recorded in similar fashion for those who can't make

it.



Meet Alexis! Alexis is the newest member of the Familial ALS team. As a SOD1 gene carrier, she has found community with the Familial team and is hoping to help brighten the ALS landscape for all those with ALS – including her brother, who was diagnosed this year at the age of 34. We're so glad to have you, Alexis! Read the rest of her story here.

# WHAT'S COMING UP?

#### Ask Me Anything ALS - Finding Meaning as a Caregiver

Join I AM ALS on December 6th at 6pm ET for a conversation where we will discuss how current and former caregivers to and loved ones of people living with ALS have coped with the mental and emotional reactions to an ALS diagnosis, the exhaustion that often accompanies caregiving, and how they prioritized finding meaning and purpose through and beyond ALS.

#### Register

## **ALS Learning Series - ALS & Exercise**

Join the Les Turner ALS Foundation for this webinar on Thursday December 8th at 1pm ET. Many people living with ALS struggle to understand whether it is OK to exercise, what kind of exercise is most beneficial, and whether exercise slows disease progression. This webinar will discuss the benefits of exercise among people living with ALS and provide insight into appropriate exercises and signs of overworking. A Q&A will follow the presentation.

## Register

#### **Twitter 101 Presentation**

Are you looking to share your story with a broader audience or increase the scope of your advocacy? If so, using social media platforms like Twitter may help. If you feel daunted or overwhelmed by using social media, you're not alone! That is why community members Mandi Bailey (aka the Self-Taught Social Media Mama) and Kerry Falzone (aka the Discreet Marketing Pro) have created an engaging presentation about

using social media, specifically Twitter, to share your story and amplify your voice. Join us on December 12th at 5pm 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 <a href="mailto:iamals.org.">iamals.org.</a>





1200 Pennsylvania Ave NW, #14135 Washington, DC 20044