



Get In. We're Ending ALS

What We're Up To

The National Institute of Neurological Disorders and Stroke (NINDS), part of the National Institutes of Health (NIH), for the first time is asking for input from the ALS community as it starts to identify the highest priorities for future research into ALS. You can respond to the Request for Information (RFI) [here](#) by the deadline of February 11.

At 12 p.m. EST on this coming Thursday February 3, I AM ALS' Director of Science and Policy Megan Miller, PhD, along with members of the Clinical Trials Community Team, will host a Community Conversation to answer your questions, like: What is NIH? NINDS? How does NIH fund grants? Why is this opportunity unique and important? And many more. Sign up to attend the Community Conversation [here](#).

Sign the Petition

The ALS community, I AM ALS and partner organizations are petitioning BrainStorm and the FDA to urgently determine a path forward for NurOwn. Please sign and share with your friends and loved ones.

[SIGN HERE](#)

COMMUNITY UPDATES



Clinical Trials Team

There's been lots of talk about Expanded Access recently with the

passage of ACT for ALS. For a refresher, check out [this video](#) of Alison Bateman-House, MPH PhD discussing expanded access in ALS.



Community Outreach Team

It's a new year, and this team is ramping up its panel project! If your church, social group, coworkers or classmates have ever wanted to learn more about ALS, request a panel of people impacted by ALS [here](#).



Familial ALS Team

This team will be hosting this month's installment of Ask Me Anything ALS, where I AM ALS' amazing community members gather to help and answer your questions about ALS. It will take place on February 25th at 12 p.m. ET. Sign up to attend [here](#).



Legislative Affairs Team

This team is working hard to make sure ACT for ALS gets fully funded in fiscal year 2022 and 2023. Read I AM ALS' joint statement with The ALS Association and the Muscular Dystrophy Association about this [here](#).



Many Shades of ALS Team

This team's next installment of "Let's Talk About It: A Mental Health Series" is going to be all about accessibility and discrimination. To prepare for this talk and get started thinking about this important topic, watch [this video](#) about physicians' perceptions of people with disabilities and their health care.



Veterans Team

This team has set its sights on passing the Justice for ALS Veterans Act. It was recently introduced in the Senate by Senators Coons and Murkowski. Click [here](#) to learn more about the bill and [here](#) to write to your elected officials and ask them to co-sponsor the bill.



Community Spotlight: Lori Larson Heller

Everyone, meet Lori! After her husband Jim was diagnosed with ALS in 2018, she left her job to be a full-time caretaker and became an ALS advocate. She's a

powerhouse member of the Legislative and Clinical Trials teams and we're so lucky to have her. Read more of her story [here](#) and her incredible op-ed in the StarTribune [here](#).

WHAT'S COMING UP?

More Than Our Stories

The fifth annual More Than our Stories conference is upon us! Every great public policy started with an individual with a good idea. Every year, ALS advocates gather from across the country to workshop their ideas and then bring them to their legislators. This year's conference will take place virtually on Tuesday, February 15 and Wednesday February 16.

[Register](#)

UC Irvine Neurodegeneration Community Workshop

UC Irvine is hosting a virtual 2-day event aimed at facilitating an exchange of knowledge and experiences between people living with neurodegenerative diseases, clinicians and researchers within the Southern California neurodegeneration community, focusing on Huntington's disease, Parkinson's disease and ALS. This event is open to the public and will include clinician panels specializing in patient management and care, talks introducing cutting-edge neuroscience research topics, a movie showing and workshops on "Visualizing Science" and "Bioinformatics." This event will take place on Friday, February 18th (9 a.m. - 5 p.m. PST) and Saturday, February 19th (9 a.m. - 1 p.m. PST).

[Register](#)

The Alex and Jaci Hermstad Rare Disease Trailblazer Series - Her ALS Story

Join members of Her ALS Story, patient advocates, clinicians and researchers to hear how a group of women are challenging ALS stereotypes and changing the face of this disease to drive female centric solutions. This event will take place on Tuesday, February 8 from 11 a.m. - 2 p.m. EST.

[Register](#)

Uncovering the Genetics of FTD/ALS

The Penn Frontotemporal Degeneration (FTD) Center is excited to open registration for its second annual familial conference, Uncovering the Genetics of FTD/ALS, on Wednesday, February 23, 3 - 5:30 p.m. EST. The Penn FTD Center understands the impact a diagnosis can have on an entire family, and this virtual, live event will address the unique challenges and situations that arise from familial or genetic disease. Whether you are impacted by familial ALS or are a health care provider, consider joining!

[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.

I AM ALS



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(Unsubscribing is not supported in previews)