



Get In. We're Ending ALS

What We're Up To

It has been months since BrainStorm met with the FDA for a Type A Meeting regarding NurOwn. Not only did BrainStorm break their promise to share the minutes of that meeting, but there has been no news or action from either BrainStorm or the FDA. The ALS community needs and deserves transparency and an Advisory Committee meeting for NurOwn. We've created two actions that will pre-populate a tweet asking for an AdComm and tagging [BrainStorm](#) and [the FDA](#). Help us demand transparency.

Tweet at the FDA and BrainStorm

The ALS clock is always ticking. Tell BrainStorm and the FDA that the ALS community deserves transparency about NurOwn's next steps.

TWEET AT
BRAINSTORM

TWEET AT THE
FDA

COMMUNITY UPDATES



Familial ALS Team

On March 22, the FDA will host an Advisory Committee meeting on Tofersen, a drug designed to treat SOD1 familial ALS. Approval of this drug would help us get one step closer to ending ALS. Join I AM ALS to watch the AdComm together at a viewing event, which will begin at

9:15am ET. Sign up to join us here: <https://iamals.org/action/tofersen-adcom/>



Legislative Affairs Team

This team never stops grinding – they are working on getting ACT for ALS funded for FY2024 and need your help! Sign up to become a constituent using this form (<https://iamals.org/action/help-the-legislative-team/>) and share, share, share it with your networks – they need people from every corner of the US.



Lou Gehrig Day Team

This team is not only working on setting up events for Lou Gehrig Day – they're also working with teams who aren't playing on June 2nd to set up alternate events! For instance, the Seattle Mariners are hosting an ALS Awareness Night on May 31st! If you're in the Seattle area, sign up to join them here: <https://iamals.org/action/mariners-als-awareness-day/>. And if your local MLB team isn't playing on Lou Gehrig Day, this is a great example of what they can do instead... hint, hint...



Many Shades of ALS Team

This team will be giving a presentation on their “Black People Get ALS Too” project to the NEALS PEACe Committee on March 27th. Wish them luck! It's gonna be amazing!



Veterans Team

Are you a veteran living with ALS? This team created an incredible guide to help you navigate the VA health system. Check it out and download it here: https://iamals.org/wp-content/uploads/2022/08/VA-Checklist-for-Veterans-Living-with-ALS_v3.pdf



Young Adult Team

This team had their first meeting last Friday and are full of good ideas that they are eager to begin working on! They meet every Friday at 3pm ET. You can join them by signing up here:

<https://iamals.org/action/youngadultteam/>

The next installment of our Ask Me Anything ALS series is coming up! In

COMMUNITY SUPPORT CORNER

in honor of Women's History Month, we are partnering with the amazing ladies at Her ALS Story to host Ask Me Anything ALS - Women Living with ALS on March 30 at 6 PM ET. This event will be by women, for women, and will address the unique challenges that women living with ALS face. **Please note, while this event is for women, we welcome male caregivers and family members to listen and learn. Sign up to join us here:

<https://iamals.org/action/ask-me-anything-als-women/>



Community Spotlight: Bob Scannell

Meet Bob! After Bob's wife Beth passed away from ALS in 2022, he jumped headfirst into the Community Outreach team. He has brought not only his great ideas, but also a kind and gentle presence. His latest project centers around asking the question "Could it be ALS?" earlier in one's diagnosis journey.

If you or your loved one was misdiagnosed with something else before receiving an ALS diagnosis, please reply to this email to connect with Bob! You can read Bob's story on our website here:

<https://iamals.org/stories/bob-scannell/>

WHAT'S COMING UP?

Tofersen AdComm Viewing Event

Join I AM ALS and other community members to watch the Advisory Committee meeting about Tofersen on Wednesday, March 22! We will be on Zoom together all day starting at 9:15am ET, when the meeting begins. Register: <https://iamals.org/action/tofersen-adcom/>

ALS and Cognitive Function

Join the Les Turner ALS Foundation for the next installment of their ALS Learning Series, taking place on Thursday, March 23 at 1 pm ET. This webinar will be led by Catherine Lomen-Hoerth, MD. She will provide an overview of ALS, including its causes and symptoms, and discuss how it affects cognitive functioning. Dr. Lomen-Hoerth will cover the latest research on cognitive changes, offer tips on managing these symptoms, and provide strategies for supporting people living with ALS and their families who are impacted by this.

Register:

<https://register.gotowebinar.com/register/7007282590976034649>

March Social Hour

This month's social hour will be on March 30th, from 4:30-5:30pm ET! Join your fellow advocates for an hour of no-agenda, no-pressure socialization. If you've never been to an I AM ALS meeting before, this is a great place to start! We can't wait to meet you.

Register: <https://iamals.org/action/social-hour/>

[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.

IAM ALS



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