

I AM ALS



Get In. We're Ending ALS

What We're Up To

The NurOwn AdComm is in two weeks, and the amazing NurOwn Working Group has some action items for you! The deadline to submit written comments to the FDA is approaching quickly. Be sure to submit your comments by September 20th to make sure they make it into the materials given to advisory committee members. Use [our guide](#) to help craft your testimony. Also, the Working Group created a [social media toolkit](#) for advocates to help spread the message about NurOwn on social media. Please check both out and SHARE – we are almost there!

Sign onto the NurOwn Statement

Help us show the world that the ALS community is watching - sign on to a collective statement asking for a transparent review of NurOwn's totality of evidence. I AM ALS will publish the statement and use it as a tool to gain the attention of the FDA, media, and other key players. Our goal is 10,000 sign-ons!

ADD YOUR
NAME

COMMUNITY UPDATES



Community Outreach Team

This team continues to build out the Tim Lowrey ALS Panel Series (TLP), with new panel presentations being booked almost weekly. Watch this

incredible [promotional video](#) that now gives organizations a taste of what to expect from a TLP. Watch the video and request a panel of your own here: <https://iamals.org/action/request-a-panel>



Legislative Affairs Team

These persistent advocates are keeping ALS funding top of mind with members of Congress to maintain funding ACT for ALS for expanded access programs (EAP). Join them by using this action to send pre-populated tweets to your members of Congress.

<https://iamals.org/action/appropriations-2023-act4als/>



The Write Stuff

The wonderfully talented Write Stuff team requests your presence at their first Literary Salon, which will be held on October 2, 2023 from 7 - 8:30pm EST. Join us for an evening featuring writers living with and impacted by ALS reading their work. Come and hear stories about ALS; stories of resilience, life, joy, and love. <https://iamals.org/action/literary-salon/>



Veterans Team

This team needs your help to make sure Congress includes ALS research funding in their budget for fiscal year 2024. Use this action to send a pre-populated tweet tagging your Congresspeople and asking them to advocate for maintaining CDMRP funding at \$40 million.

<https://iamals.org/action/appropriations-2023-cdrmp/>



Whether or not to get a tracheostomy is a very personal decision that every person living with ALS may eventually face.

We've compiled a list of resources that can help you make that decision and help you prepare for the procedure. Check it

out: <https://iamals.org/get-help/tracheostomy-and-als/>

Community Spotlight: Pat Dolan

The man, the myth, the legend! You've probably heard about Pat and his incredible geospatial mapping of ALS. He



presented his most recent project, Mapping the ALS Registry, at the annual CDC National ALS Registry Symposium in August. You can watch the full video of his presentation here: <https://www.youtube.com/watch?v=1vZd74qdl68> Thanks for all you do, Pat!

WHAT'S COMING UP?

NurOwn AdComm Viewing Event

On September 27th, 2023, the U.S. Food and Drug Administration (FDA) will host an Advisory Committee Meeting on BrainStorm's NurOwn. No need to watch this event solo – join IAA and the ALS community for a watch party for this monumental AdComm.

[Register](#)

September Social Hour

This month's IAA social hour will be on Thursday, September 28th at 3pm ET! Join your fellow advocates from across the ALS community for an hour of camaraderie and friendship. No agenda, no pressing work – just fun! If you've wanted to get involved with IAA but aren't sure where to start, Social Hour is a great first stop.

[Register](#)

Personalized speech recognition models and other communication tools for pALS

This webinar from EverythingALS features Team Gleason Executive Director Bob McDonald. Bob focuses on projects that apply AI techniques to solve problems related to disabilities and social good, including improving speech recognition for those with impaired speech as well as driving innovation in other assistive technologies. This webinar will take place on September 20th at 4pm 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.

I AM ALS



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