IAM ALS



Get in. We're Ending ALS

What We're Up To

It has been a busy few weeks at I AM ALS! Between the #ALSinDC Flag Event in May and Lou Gehrig Day celebrations across the country throughout June, this community has mobilized and accomplished some truly incredible things. We'll soon share a detailed impact report, but in the meantime, pat yourself on the back – you deserve it! Thank you for everything. We can't wait to keep moving mountains with you!

Contact Your Congresspeople

Use this action to send a prepopulated tweet to your congresspeople asking them to double funding for CDMRP's ALS Research Program for FY 2024.

SEND THOSE TWEETS!

COMMUNITY UPDATES



Community Outreach Team

A team member had the idea for an Artistry of ALS project, and it has come to fruition in just a couple of months! The project includes a virtual gallery (available now) and an artists' panel discussion on June 22nd from 6-7:30pm ET. https://iamals.org/artistry-of-als/



Familial ALS Team

This team has embarked on a new series of community events, and the <u>first two have been amazing!</u> You can watch the recording of the first one,

"What's In a Gene? An Introduction to Familial ALS" on our YouTube channel here: https://www.youtube.com/watch?v=MbE05z2-Gj0. A recording from the June 15th event, "Big Feelings in Familial ALS: A Community Conversation about Generational Trauma" will be available soon.



Legislative Affairs Team

The top priority for these amazing advocates is securing funding for the ACT for ALS for FY2024. You can help the legislative team build relationships with your representative and secure ALS funding by filling out this form: https://iamals.org/action/help-the-legislative-team/



Lou Gehrig Day Team

HUGE thanks to this team for making Lou Gehrig Day 2023 a success! They brought the community together to celebrate Lou Gehrig and honor those we love who are living with and who we have lost to ALS, as well as raise ALS awareness all over the country. So step up to the plate and join this awesome team as they recap this year's efforts and start planning for next year: https://iamals.org/action/lou-gehrig-day-team/



Many Shades of ALS Team

The Many Shades Team is hard at work on the next installment of their mental health series, *Let's Talk About It (LTAI)*. The next LTAI will take place on July 24th from 6-7:15pm ET and will center on coping with the progressive loss of function and independence that results from ALS. We hope to see you there! https://iamals.org/action/lets-talk-about-it-july/



Veterans Team

A moment we've been waiting for – the Justice for ALS Veterans Act has been reintroduced in Congress! We need your help to make sure it becomes law this session. Use this form to send a pre-populated email to your members of Congress encouraging them to support this critical legislation. https://iamals.org/action/justice-for-als-veterans-2023/



Young Adult Team

The Young Adult Team is in the process of developing a social media campaign to shed light on the experiences of young adults in the ALS space and recruit more members. If you're 18-29 years old and interested in working on projects like this one, we hope you'll join the team! https://iamals.org/action/youngadultteam/



You've heard about our amazing support groups, but did you know about our Loved Ones group? These loved ones of people living with ALS meet on the third Wednesday of every month from 1-2pm ET. The next session will be on June 21st. Sign up here:

https://iamals.org/action/join-asupport-group/



Community Spotlight: YOU?

Ever dream of being in the spotlight? On stage, in NYC, surrounded by adoring fans? Well, we probably can't help with that, but we would love to see you step into the spotlight for our next I AM ALS Talent Show! Share your hidden (or not so hidden) talents with your fellow advocates, or just come to watch the show on July 26th. Sign up here: https://iamals.org/action/talent-show/

WHAT'S COMING UP?

June Social Hour

This month's social hour will take place on Tuesday, June 20th, from 4-5pm ET. Come join us for an hour of unstructured time to kick back with your fellow advocates. Hint: if you've been wanting to get involved with I AM ALS teams but weren't sure where to start, this is a great first step! Register

A Pulmonologist Explains Tracheostomy and Invasive Ventilation for People Living with ALS

This webinar from the Les Turner ALS Foundation's ALS Learning Series

will take place on Monday, June 19th, at 1pm ET. Not everyone with ALS will need or choose to have a tracheostomy, but there may come a time when it's necessary for continued breathing. Join Lisa Wolfe, MD, for a pulmonologist's breakdown on respiratory management for those with increased ventilation needs. Community resources will be shared.

Register

Understanding Statistical and Clinical Significance

What do researchers and scientists mean when they describe a study as "statistically significant?" How do people with ALS and clinicians understand whether or not a treatment option is "clinically significant?" Join NEALS on Wednesday, June 21st, at 1pm ET for a webinar and panel discussion that will provide a framework for understanding the results of ALS clinical trials, using several recent studies as examples.

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.





