I AM ALS

Get In. We're Ending ALS

What we're up to:

The deadline for completing I AM ALS's community survey is Friday, September 8th and we want to hear from you! Those who complete the survey (and those who already have) will be entered into a raffle to win an I AM ALS zip-up hoodie. We need your help and insights to keep moving mountains! Fill out the survey and enter to win here: https://iamals.org/action/community-survey/

Sign on to the NurOwn Statement

Help us show the world that the ALS community is watching and needs 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.

ADD YOUR NAME

COMMUNITY UPDATES

Legislative Affairs Team

The top priorities for this team are to secure 75M funding for the ACT for ALS for FY2024 and keep ALS research at $40M for the CDMRP. They're currently thanking legislators for their support and encouraging full FY24 funding. The team is also encouraging written comments to the FDA about NurOwn prior to the September 20th deadline. Read I AM ALS' guide and submit your comment here: https://iamals.org/updates/guide-to-submitting-written-testimony-to-the-fda-about-nurown/

Lou Gehrig Day Team

Planning for the Lou Gehrig Day 2024 has already begun! Come join our all star lineup to raise ALS awareness, promote Lou Gehrig Day, celebrate his legacy, and unite the ALS community for a memorable day. Sign up: https://iamals.org/action/lou-gehrig-day-team/

Many Shades of ALS Team

The Many Shades of ALS Team is hard at work on their next Let's Talk About It! The next installment of their mental health series will occur in November and discuss inclusivity during the holidays and ensuring that everyone has a seat at the table. Stay tuned for details!

The Write Stuff

Check out the latest blog posts, the new forum page, and community discussions on this team's website! For some good reads and to meet the Write Stuff Team, check it out: https://www.alsthewritestuff.com/

Veterans Team

This team recently attended the PVA Summit and presented the ALS Veteran Champion Award to Dr. Huned Patwa. Dr. Patwa was recognized for his outstanding contributions to ALS research, his work on the first ALS VHA directive, and so much more. Check out photos of the award presentation here. If you know of a veteran champion in the ALS space that deserves recognition, nominate them for the Veteran Champion Award here: https://iamals.org/action/als-veteran-champion-award/

Young Adult Team

The Young Adult Team is preparing to collaborate with other ALS organizations to host a community conversation on mental health and young adults in the ALS space. This conversation will allow others to better understand the young adult perspective, one that is often overlooked or hidden within the ALS community. Join the team: https://iamals.org/action/youngadultteam/

Learning more about your or your loved

one's ALS diagnosis and care plan can empower you to actively participate in planning care. Sometimes it's hard to know where to start or what questions to ask, so we have created a series of checklists with questions to ask your care teams to help get you started. Check it out: **https://iamals.org/get-help/how-to-build-your-care-plan/**

Community Spotlight: Gia Polo

Gia's dad Carl passed away in November 2022 from ALS. Since then, Gia has been honoring his memory in so many ways – not just by living her dreams and succeeding, but by advocating to end the disease that took his life. Check out Gia's interview on Cleveland.com, **"Cleveland hotelier fights against ALS, the illness that took her father."**

WHAT'S COMING UP?

Mothers of ALS - Virtual Gathering

Compassionate Care ALS (CCALS) is launching this monthly gathering series for mothers of people living with or who have passed from ALS. Carolyn Parrott, whose daughter passed away in 2021 from bulbar-onset ALS, expressed a longing to connect with other mothers in solidarity. Join Carolyn and the CCALS team for this unique opportunity. The first session is on September 7th at 4pm ET.
Register

Nutrition: Journey from Beginning to End

This webinar is part of the Les Turner ALS Foundation's ALS Learning Series. In this installment on September 14th at 12pm ET, Dr. Edward Kasarskis will discuss nutrition and hydration, constipation, and bowel

management in ALS.
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.