IAM ALS



Get In. We're Ending ALS

What We're Up To

This week, the FDA had a Type A meeting with BrainStorm, the makers of NurOwn. I AM ALS is hopeful that this meeting was productive and that the FDA decides to hold a public, transparent Advisory Committee meeting in the near future. To keep up with any breaking updates, follow I AM ALS on Twitter here.

New support group: Veterans!

We have added a new support group specifically for Veterans living with ALS, cofacilitated with the PVA. It takes place on the fourth Wednesday of every month from 1-2pm EST. Please join us!

SIGN UP

COMMUNITY UPDATES



Clinical Trials Team

This team wants YOU to join them! You can help them make waves as they tackle their new goals for 2023. Learn more about what they do and how you can join them <u>here</u>.



Community Outreach Team

All-star team member and podcast host Lorri Carey has brought us yet another beautiful episode of *I'm Dying to Tell You*, this one featuring Kylan

Morris, who lost her mom Sandy to ALS last year. Take a listen here.



Legislative Affairs Team

This team is gearing up for another year of advocacy by getting to know the new 118th Congress. You can help them by signing up to be a constituent on call in your district! Learn more and sign up here.



Thank You Squad

The results are in! In 2022, this team wrote... drumroll please... 4,407 thank you cards!!!! That's a LOT of thanking, so we'll take our turn and say: THANK YOU to the Thank You Squad!



Veterans Team

This team is seeking nominations for their next ALS Veteran Champion Award recipient! If you know someone who provides or helps plan excellent care to people living with ALS and their loved ones, does an excellent job educating people living with ALS about their disease and resources, and/or goes above and beyond to provide the best possible experience for people living with ALS, please consider nominating them here.



Are you a mother of an adult child living with ALS? The Peer Support Initiative needs people just like you to serve as mentors to others in the community who are experiencing similar challenges. If you are interested in becoming a peer mentor, please apply here!



In Memoriam: Austen Eadie-Friedmann

We are so sad to share the passing of Austen Eadie-Friedmann. Austen came to I AM ALS with a can-do attitude and determination to make a difference. He also encouraged frank conversations about terminal illness, providing muchneeded honesty and candor. Austen is survived by his loving husband and college sweetheart, Billy. You can read

Austen's obituary here.



In Memoriam: Danny McClellan

We are also deeply saddened to share the passing of Danny McClellan. "Danny Mac" was a kind and loving man to all, and generously gave his time to others through teaching Sunday school and coaching youth basketball. He is incredibly missed by his family and community. His daughter Kristen joined the I AM ALS Thank You Squad in 2021 to share his light and his story, and we are so grateful. You can read Danny's obituary here.

WHAT'S COMING UP?

Ask Me Anything ALS - Feeding Tubes and Nutrition

The next installment of Ask Me Anything ALS will take place on January 31st at 6pm ET! This time, a panel of people living with ALS and Sarah Luppino, MSN, NP-BC of Mass General will discuss feeding tubes and nutrition – the decision to get a feeding tube, how to maintain one once you have it, and more.

Register

ALSUntangled – Vitamins and Supplements in ALS

In this webinar from NEALS (Northeast ALS Consortium) on January 18th at 12pm ET, Dr. Richard Bedlack will review ALSUntangled, including how patients and families can use it to make more informed decisions about vitamins and supplements. He will show how he guides patients at Duke who want to self-experiment with these products and share his current most and least favorite ones.

Register

Twitter 101 was so successful that we're taking on Instagram! Join Self-Taught Social Media Mama Mandi Bailey and Discreet Marketing Pro Kerry Falzone for a crash-course in how to utilize Instagram for advocacy on January 26th at 5pm 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.



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