IAM ALS



Get In. We're Ending ALS

What We're Up To:

Amylyx Pharmaceuticals has announced that the FDA will convene a second Advisory Committee Meeting (AdCom) to review AMX0035 data as part of the FDA approval process. The AdCom will take place on September 7. While there is still much we don't know about this unprecedented second AdCom, we are intent on ensuring the community's voice is heard and continuing our push for approval. We will post updates on our social media platforms as soon as we know more – stay tuned! Read the open letter to the FDA from us and other ALS organizations here.

Join a Support Group

If you are struggling with the impact ALS has had on you or a loved one, we are here to support you. Whether you are living with ALS, are a caregiver, are bereaved, or are otherwise impacted, please check out our ALS support groups.

GET IN TOUCH

COMMUNITY UPDATES



Clinical Trials Team

This team is getting excited about the 2022 International Symposium on ALS/MND, and they want you to be a part of it! Apply to the Patient Fellows Program by the deadline of August 19 – if selected, you will be granted free admission to the symposium. Apply here.

Familial ALS Team



This team wants to share an exciting development in genetic C9 ALS – the EU has given a large grant to companies working to develop a vaccine for C9 ALS! Learn more here.



Legislative Affairs Team

This team is working hard to make sure ALS champions in Congress know about the FDA's consideration of AMX0035 and the second Advisory Committee Meeting in September. Want to help? Join the team <u>here</u>!



Many Shades of ALS

Black in Neuro Week is almost here!! This team has been hard at work with Black in Neuro to make this week of education and discussion a success. Team member Bernadine Okeke will be joining their panel on Neuro Racism on Wednesday July 27th where they will discuss how racism translates into misdiagnoses or lack of diagnosis in neurology and psychiatry. Register for the panel here and check out the rest of the events here.



Veterans Team

This team would love your help making sure the Justice for ALS Veterans Act gets passed in Congress. Use the form <u>here</u> to write to your congresspeople and ask them to make the Justice for ALS Veterans Act a priority.



NEW: Community Support Corner!

There's nothing quite like learning from someone who has a similar experience or connection to ALS as you. Our Peer Support Initiative is designed to help you connect and get support from someone who gets you. Learn more about getting matched with a trained peer mentor <u>here</u>.



In Memoriam: Tom Garey

It is with deep sadness that we share the passing of Tom Garey. Tom was a United States Air Force veteran, a loving husband to his wife Lara, and an amazing father to his son Trey. Tom and his family worked tirelessly to improve the lives of veterans living with ALS. He was an incredible person and will be sorely missed. Read Tom's story in his own words <u>here</u>, and his obituary <u>here</u>.



In Memoriam: Olin Thompson

We are heartbroken to also share the passing of Olin Thompson. Olin spent his life striving for justice and fairness as a lawyer and Public Defender. He loved playing cards, music, nature, and baseball, but most of all his wife, Christa, and his three sons. Olin's obituary reads, "Olin would like you all to hug your kids daily and say 3 or 4 positive things for each negative. 'It's really hard! But you can do it."" In his memory, let's all fulfill Olin's wish today and tomorrow. Read the rest of Olin's obituary here.

WHAT'S COMING UP?

Ask Me Anything ALS - Communication Technology

Join I AM ALS community members, Team Gleason, and Bridging Voice for Ask Me Anything ALS – Communication Technology on July 28th at 5:30 p.m. ET to learn from people who are navigating and providing communication solutions to the ALS community every day. **Register**

NEALS Webinar: Genes in ALS

This webinar will take place on July 28th from 1 - 2 p.m. ET. It will provide an approachable overview of the major genes involved in ALS: what those genes are, how they lead to ALS, and what ideas they are giving scientists for treating all forms of ALS. There will be time at the end of the presentation for questions. Register

ALS Town Hall: Discussion on Tegoprubart Phase 2a Results

Join ALS TDI at this installment of their ALS Town Hall series on July 27th from 3 - 4 p.m. ET. Tegoprubart is a potential treatment for ALS that was invented at ALS TDI and recently completed a phase 2a trial carried out by Eledon Pharmaceuticals. The discussion will be led by Eledon's Chief Executive Officer, Dr. David-Alexandre C. Gros, and President and Chief Scientific Officer, Dr. Steve Perrin, who will provide an overview of the drug mechanisms and the trial results. **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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