



Get In. We're Ending ALS

What We're Up To

Last week, the FDA approved AMX0035 (now known as Relyvrio) for the treatment of ALS! This is a huge step forward and provides tangible hope that ALS will one day be a chronic condition. Amylyx Pharmaceuticals has several programs to help people living with ALS access Relyvrio. The I AM ALS Support Team is here to help you navigate those programs!

Questions about Relyvrio?

Our ALS Support Team can help! Reach out to them any time by email at gethelp@iamals.org, or click the button below to fill out an intake form.

REACH OUT

COMMUNITY UPDATES



Clinical Trials Team

This team is thrilled to see that the NINDS has awarded their first expanded access grant under ACT for ALS to the HEALEY Platform Trial. Check out I AM ALS' [press release](#) for more information.



Community Outreach Team

This team brought us yet another great installment of the Tim Lowrey ALS Panel Series, this time for speech language pathology students at University of Buffalo and Buffalo State. Check out the video of the panel [here](#), and request your own educational ALS panel for your class or

organization [here](#).



Familial ALS Team

The team is seeking feedback from *pre-symptomatic* gene carriers in the ALS and/or FTD community regarding their desire and preference in accessing ALS treatments! If you or anyone you know is at risk for genetic ALS and/or FTD, please fill out the anonymous survey using [here](#). If not, help us amplify this survey by sharing this Tweet from Familial ALS Team Co-Chair, Jean Swidler, [here](#).



Many Shades of ALS Team

This team continues to collaborate with [Black in Neuro](#). This time they're addressing racism and disparities in healthcare and research within the Black community impacted by ALS. Learn more and sign up to attend [here](#). All are welcome.



Veterans Team

This team is seeking nominations for their ALS Veteran Champion Award! This award recognizes individuals and organizations that distinguish themselves by going above and beyond to address the needs of veterans living with ALS and their loved ones. If you have a champion in mind, please nominate them [here](#).



In Memoriam: Jay Kenney

We are incredibly sad to report the passing of Jay Kenney. Jay was one of the kindest, warmest, sweetest people you could ever meet. He had a laugh and a smile that lit up a room, and had a knack for making everyone feel welcome.

He also told the WORST (and best) jokes. He was a Veteran and a valued member of the Veterans Team, and was constantly making us smile in Social Hour. We can't describe how much we miss him. Read Jay's story [here](#), and his obituary [here](#).

WHAT'S COMING UP?

No Ordinary Campaign Screening at the Heartland International Film Festival

I AM ALS co-founders Brian Wallach and Sandra Abrevaya are the subjects of this new documentary, screening at the Heartland Film Festival on October 14th, 15th, and 16th. The film documents Brian's journey with ALS, the founding of I AM ALS, and the movement to change the rare disease landscape.

[Register](#)

ALS TDI Summit

On Friday, October 14, join the ALS community and ALS TDI for the ALS TDI Summit, a free conference that aims to inform and empower the ALS community by educating attendees about ALS TDI's latest work to discover and develop effective treatments for ALS. The Summit invites all members of the community to learn about ALS TDI's cutting-edge approach to ending ALS, in person and virtually.

[Register](#)

Celebration of Life

Join the Les Turner ALS Foundation on Saturday, October 22 for their annual Celebration of Life. This annual service honors those we have lost to ALS. It will be held online via Facebook Watch and recorded for those who cannot attend the live event.

[Register](#)

Voice Banking Webinar

Join the International Alliance of ALS/MND Associations for this webinar on October 12 to learn about voice banking technology, how it works, when in the ALS/MND journey should it be done, and how to get access. Note: to accommodate international attendees, this webinar will take place from 7 - 8 a.m. EST.

[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



1200 Pennsylvania Ave NW, #14135 Washington, DC 20044