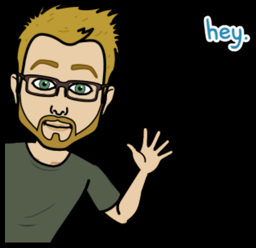
I AM ALS



Get In. We're Ending ALS

What We're Up To

We would like to thank everyone who attended the recent town hall with BrainStorm Cell Therapeutics and everyone who submitted questions. Some of what was discussed was difficult to hear, but we are glad to know more about the path forward for NurOwn and BrainStorm's plans for the future. The recording will be available ASAP. Subscribe to our YouTube channel to be notified when it is posted: https://www.youtube.com/iamals

Peer Mentors Needed

The Peer Support Initiative is in need of people to serve as mentors who are spouses of people living with ALS, or parents of a person living with ALS. If you fit these criteria, please apply!

APPLY HERE

COMMUNITY UPDATES

Clinical Trials Team

Several new updates have recently been added to ALS Signal: a new uniQure Phase 1/2 trial has been listed for gene therapy AMT-162 (not yet recruiting), a Zydus Phase 2 trial for therapy ZYIL1 started recruiting in India, and Corcept Therapeutics Phase 2 trial for dazucorilant is now recruiting patients at its first US site in New Jersey. Big shoutout to team member Rob, who makes sure Signal is as up to date as possible! Check out these new additions: https://iamals.org/get-help/als-signal-clinical-research-dashboard/

Community Outreach Team

This team helped put together an incredible event that's coming up next month: a Q&A with the stars and directors of the film *Matter of Mind: My ALS!* Sign up to join them on December 1st and you will receive an email link to watch the film in the weeks leading up to the event. Then all will come together on December 1st for the Q&A. You won't want to miss it! Sign up: **https://iamals.org/action/matter-of-mind-my-als/**

Legislative Affairs Team

This persistent and hardworking team continues to connect with members of Congress to keep ALS funding a priority. They are also busy reaching out to key members of the Senate to support the Promising Pathway Act (PPA). Want to help support PPA today? Ask your legislators to support the bill: **https://iamals.org/action/promising-pathway-act/**

The Write Stuff

Team members Katrina Byrd, Elin Adcock, and David Buseck all have pieces published in the November/December issue of Beneath Your Beautiful magazine! Read their incredible pieces in the full issue of the magazine here: **https://beneathyourbeautiful.org/magazine**

Veterans Team

With 2023 coming to a close, we are going all out to get legislation passed before the end of the year. The Justice for ALS Veterans Act needs your support. Ask your members of Congress to support this bill using this action: **https://iamals.org/action/justice-for-als-veterans-2023/**

Youth Lou Gehrig Day Team

Let's give a BIG welcome to the new Youth Lou Gehrig Day Team! This small but mighty team is looking for new community members to join them as they help youth T-ball, little league, and softball leagues throughout the country hold Lou Gehrig Day celebrations to raise awareness of ALS and celebrate Lou's legacy. Learn more: **https://iamals.org/action/youth-lou-gehrig-day/**

One-on-one support is an incredibly valuable tool for people impacted by ALS. We match mentors and mentees who have similar life experiences to provide

COMMUNITY SUPPORT CORNER

unique support. If you would like to serve as a mentor, especially if you fit any of the criteria listed above, please apply! **www.surveymonkey.com/r/IAA-Mentor**

Introducing: Patrick!

Patrick Nicholas has joined the ALS Support Team as ALS Support Lead! Patrick is an experienced social worker, community organizer, and patient advocate with a passion for health and social equity. In his role as ALS Support Lead, Patrick provides individual and group support for all who are impacted by ALS while implementing program leadership and development within community support services. Please join us in welcoming Patrick!

WHAT'S COMING UP?

Podcasting Panel - November 14th, 3pm ET

The ALS Podcasting Panel is coming up next week! Part 1 of this 2-part series will feature a group of amazing podcast hosts working within the ALS space. Panelists will include Mary Hahn Ward, co-host of ALS Caregivers and Beyond; Dave Stanley and Alison Burell, hosts of I Lost My Person; Lorri Carey, host of I'm Dying to Tell You; James Smith, host of Beyond MND; and Maria Aleandra Fernandez and Jules Rodriguez, hosts of The Couple Shift. You won't want to miss it!
Register

The Art of Showing Up - November 15th, 7pm ET

This webinar from Everything ALS will feature Ron Hoffman, Founder and Executive Director of Compassionate Care ALS. In Ron’s words, the webinar will be about “26 years of tending to and caring for pALS and cALS. Would you like to know what I know?”
Register

Men of ALS - November 16th, 2pm ET

This event series is hosted by Compassionate Care ALS. The event description says it best: “Enjoy the connection and unique perspective of other men living with ALS, male caregivers of persons living with ALS, sons of those with ALS, or any man touched by the disease. We will gather in council to share our experiences with the broad motivation to bring heartfelt connections and healing to the ALS journey.”
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