



Get In. We're Ending ALS

What We're Up To

We lost so many incredible people to ALS in 2022. This community felt that loss every day and wanted to do something to honor those that are no longer with us. The Community Outreach Team had the wonderful idea to remember these folks in an [In Memoriam video](#). Please join us in remembering those we have lost to ALS in 2022.

Feeding Tubes & Nutrition Part 2

We got so many questions at this week's Ask Me Anything that we're having a Part 2! Join us on February 16th at 6pm ET for more about feeding tubes and nutrition.

[REGISTER](#)

COMMUNITY UPDATES



Familial ALS Team

This team has new leadership and a new meeting time – Mondays from 4 - 5 pm ET! If you'd like to join this team as they set their goals for 2023, sign up [here](#).



Legislative Affairs Team

This hardworking team is finalizing their 2023 priorities and preparing to build new relationships with new members of Congress. Join this team of mountain movers by signing up [here](#).



Lou Gehrig Day Team

This team is busy educating and collaborating with MLB teams to bring the ALS community together for a day of fun and advocacy all over the country in June. Come join this amazing team [here](#) and join the fun as they plan pre-game, gametime and post- game activities.



Many Shades of ALS Team

This team is excited to present their first Let's Talk About It event of 2023! This installment of their mental health series will take place on February 7th at 5:30pm ET, and the focus will be "Bringing Life into Living with ALS/PLS." Sign up [here](#) to join them!



Veterans Team

Team members Juan Reyes and Katrina Byrd put their heads together and composed a beautiful piece as part of Bullets and Band-aids, an art and storytelling experience featuring collaborations between veterans and civilian writers and artists. Katrina helped Juan write his story and lent her storytelling skills to several other veterans involved in making the anthology. You can learn more about this organization [here](#).



Young Adult Team

New team just dropped! This team is looking for participants ages 18-29 impacted by ALS who would like to join. Meeting date and time are still being determined, so sign up [here](#) to join and receive updates once a date and time are chosen.



The cold winter months can be especially challenging to our mental health. We recommend this [great article](#) from [Your ALS Guide](#) featuring an interview with Mary Holt-Paolone, MS RN, who has supported families impacted by ALS for over 15 years. We hope this will be a helpful resource when it comes to taking care of your mental health.

[Community Spotlight: Stacie Votaw](#)
Stacie has started writing about various aspects of her life with ALS. Her pieces



are beautifully written and incredibly powerful – she shares her feelings, good and bad, and doesn't sugar-coat any aspect of life with ALS. Click to read her latest piece, [“Transforming Oxygen”](#) (and see her original art that accompanies the piece), and her previous piece, [“Can You Speak ALS?”](#)

WHAT'S COMING UP?

Ask Me Anything ALS - Feeding Tubes and Nutrition Part 2

We got so many questions in Part 1 that we're having a Part 2! **Note: please register again if you would like to attend Part 2, even if you registered for Part 1.** On February 16th at 6pm ET, join the I AM ALS community and Sarah Luppino, MSN, NP-BC, Mass General Hospital Healey Center for ALS, for a conversation on feeding tubes and nutrition. You'll learn from the panelists more about how and why they decided to get feeding tubes, the advantages and disadvantages, how they maintain their feeding tubes, and more.

[Register](#)

Let's Talk About It: A Mental Health Series - Bringing Life into Living with ALS/PLS

Receiving an ALS diagnosis is devastating for many reasons, including the knowledge that with a progressive loss of function will potentially come the loss of employment and much-loved activities. This is why the Many Shades of ALS (MSOA) team here at I AM ALS wants to talk to you about a powerful antidote to the despair of ALS diagnosis and progression: staying engaged in life. This will look different for different people, but remaining engaged and busy can be a powerful way to find purpose, remain physically and mentally healthy, and come to terms and cope with the reality of living with ALS. Join the team on February 7th at 5:30pm ET for this powerful conversation.

[Register](#)

More Than Our Stories

The sixth annual More Than Our Stories conference is happening in Washington DC and virtually on February 14th, with a Hill Day on February 15th! Join a group of advocates for an in-depth discussion of each person's ideas and policy priorities, then take those priorities to Congress.

[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



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