

I AM ALS



Join us. We're Ending ALS

What We're Up To

Get your peanuts and crackerjacks – Lou Gehrig Day 2022 is ramping up! ALS advocates across the US (and Toronto!) are planning events at ballparks, bars, breweries, Little League games and more. Join us at an event near you, and don't forget to [submit your ALS baseball story!](#) Plus – this is the last week to [pre-order your swag](#). All pre-orders get a free pair of sunglasses! Order now before quantities become limited!

Join us on Lou Gehrig Day!

See if there's a Lou Gehrig Day event happening near you – and if there isn't, make one!

[CHECK IT OUT](#)



NEW INITIATIVE: Outreach Advocate Program

We just launched an exciting program designed to help expand I AM ALS support services and programs and raise ALS awareness in communities that have historically and currently experience a lack of access to support services, appropriate care and healthcare information: Black and/or African American people and people who live in cities that are far from an ALS clinic. We are seeking outreach advocate volunteers to help us shape this program and transform ALS care. [Learn more and apply!](#)

COMMUNITY UPDATES



Clinical Trials Team

This team would love your help signing and sharing a [petition](#) letting drug companies know that Open-Label Extensions (OLEs) are vital and should be part of all ALS clinical trials. OLEs allow people who have participated in a clinical trial to retain access to the drug or treatment after the trial has ended, even if the drug does not move forward.



Community Outreach Team

Outreach team members are helping to amplify a new and amazing resource: the recording of the event [Ask Me Anything: Tracheostomy Part 2!](#)



Familial ALS Team

This team has been hard at work finding Genetic ALS Observational Studies and adding them to [ALS Signal](#). These studies seek to better understand genetic and familial ALS, often in people who have not yet developed ALS symptoms. Check them out [here](#).



Many Shades of ALS Team

This team is back at it with another installment of Let's Talk About It: A Mental Health Series! This session's topic is Youth with ALS. Members from the Many Shades team and a mental health professional will discuss topics such as the myth and misconception that ALS is an old white person's disease, and how disbelief from doctors delays diagnosis for youth living with ALS. Learn more and sign up to attend [here](#).



Veterans Team

Last year, the Veterans Team partnered with I AM ALS Community Support to create an amazing mental health resource that addresses difficult topics like depression and suicidal ideation in the context of ALS. Check it out [here](#).



In Memoriam: Matt Toole

It is with deep sadness that we share the passing of Matt Toole. Matt lived with ALS for over a decade and was an advocate for much of that time. He recently joined I AM ALS' Community

Outreach Team, Legislative Affairs Team and Clinical Trials Subsquad. He immediately made an impression as someone warm, kind and funny -- his smile lit up every room he was in. He is survived by his wife Karen and two children, all of whom he adored. Read Matt's story in his own words [here](#).

WHAT'S COMING UP?

Let's Talk About It: A Mental Health Series - Youth with ALS

Let's Talk About It returns this Wednesday, April 13 at 12 p.m. ET for another installment! This one will be about Youth with ALS and will discuss topics like: the myth and misconception that ALS is an old white person's disease, how disbelief from doctors impacts youth and family members and delays in diagnosis.

[Register](#)

Where's Our Operation Warp Speed?

NYU Medical's CUPA team (Compassionate Use and Preapproval Access) will meet this Tuesday, April 12 at 12 p.m. ET to discuss ethical and practical considerations when adjusting Covid-19 pandemic approaches in health and medicine to non-pandemic diseases like ALS. The panel will feature medical ethicists, a patient advocate and a representative from a pharmaceutical company.

[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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