

I AM ALS



Get in. We're Ending ALS

What We're Up To:

Incredible community member Maceo Carter has turned frustration into action after United Airlines broke his power wheelchair not once, but *twice*. This happens far too often, adding additional anxiety and stress to wheelchair users as they travel. Check out Maceo's op-ed in *AZ Central* [here](#). With this and similar situations in mind, the **Air Carrier Access Amendments Act** was born. This legislation intends to strengthen the existing Air Carrier Access Act by extending the rights of disabled people during air travel and creating multiple pathways for accountability. Read more about the bill [here](#).

Share the Air Carrier Access Amendments Act

This bill requires all airplanes to meet accessibility standards for safe and effective boarding and deplaning, seating accommodations, accessible lavatories, and better stowage options for assistive devices, such as power wheelchairs. Ask your legislators to support this bill.

WRITE YOUR LEGISLATORS

COMMUNITY UPDATES



Clinical Trials Team

Amazing team member Irene Shapiro was published in *STAT News* with an informative article about the Morris ALS Principles! Check it out [here](#).



Community Outreach Team

This team brought the Tim Lowrey ALS Panel Series to the NYU Grossman School of Medicine on August 3rd and it was a rousing success! To request a similar panel for your school, job, organization, or any other group, click [here](#).



Familial ALS Team

This team wants you to know the exciting news about Biogen's drug, tofersen, which is designed to treat SOD1 genetic ALS. Toferson has been granted priority review by the FDA. Learn more about tofersen and the FDA timeline [here](#).



Legislative Affairs Team

This team wants you to check out the Justice for ALS Veterans Act and encourage your elected officials to support this important legislation. Learn more about the bill [here](#), and send a message to your congresspeople [here](#).



Many Shades of ALS Team

This team partnered with Black In Neuro for an important NeuroRacism panel as a part of Black In Neuro Week 2022! Team member Bernadine Okeke spoke about misdiagnosis and delayed diagnosis in ALS within the Black community. Watch the event [here](#).



Thank You Squad

This squad has grown so much that they needed a co-chair to help lead them! Please welcome Abby Sims, new co-chair of the Thank You Squad!! We appreciate Abby's dedication to the squad and are delighted to welcome her to the leadership team.



Veterans Team

This team presented their inaugural Veteran Champion Award to Leah Darling at the VA Medical Center in Indianapolis, IN! Thank you, Leah, for your dedication and compassion serving veterans living with ALS and their loved ones. Watch the presentation of the award on our Facebook page [here](#).

The I AM ALS Peer Support Initiative is always looking for more amazing people impacted by

COMMUNITY SUPPORT CORNER

ALS to become mentors to offer support and share their lessons learned with someone who has a similar connection to ALS. While the program currently has a specific need for mentors who are men living with ALS, and mentors who are caregivers for young children, we welcome anyone impacted by ALS to join as a mentor. If you or someone you know would like to become a mentor, please sign up [here](#).



Community Spotlight: Bernadine Okeke

Meet Bernadine! Bernadine is a member of the Many Shades of ALS team at I AM ALS, and she was recently a rockstar panelist on Black In Neuro's NeuroRacism panel where she addressed disparities in neuroscience, and specifically ALS. You can watch the entire panel on YouTube [here](#).



In Memoriam: Jay Payne

It is with deep sadness that we share that community member, Jay Payne, passed on July 24, 2022 surrounded by his family. Jay was an incredible father and husband and will be deeply missed by his family and friends. You can read his obituary [here](#).

WHAT'S COMING UP?

An Overview of Voice and Message Banking for People Living with ALS

This webinar from the Les Turner ALS Foundation will discuss the differences between voice banking, message banking, and double dipping, as well as how to get started, what equipment is needed, and the future of voice recognition technology. Questions, answers, and discussion will follow the program. This webinar will take place on August 18th from 12-1 p.m. ET.

[Register](#)

ALS TDI Walk for Research

This annual 4-mile walk through Newton, MA will take place on Sunday, August 28th, beginning at 10 a.m. ET. Proceeds will benefit ALS TDI and their work to end ALS.

[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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