# IAM ALS



# Get In. We're Ending ALS

#### What We're Up To

Last week, hundreds of advocates joined us in Washington, DC and on our livestream for an unforgettable day. Surrounded by 6,000 blue flags, many bearing the names, ages of diagnosis, and ages of death of those with ALS, advocates from across the country spoke from the heart to demand change. Thank you, from the bottom of our hearts, to everyone who joined us. Together, we will end ALS.

### Fuel the ALS Revolution for Lou Gehrig Day!

We've launched a new tool that makes it fun and easy to fundraise! Start a team with your book club or coworkers, or strike out on your own – together we can knock ALS out of the park!

CHECK IT OUT

## **COMMUNITY UPDATES**



#### **Clinical Trials Team**

This team met with Woolsey Pharmaceuticals, who were seeking feedback for trial design for ALS. They are interested in patient-centric trial design (as they should be) and knew that working with people living with ALS would be crucial to making that happen! Check out ALS Signal for an up to date list of ALS clinical trials and studies <u>here</u>.

#### Legislative Affairs Team



This team continues to hunt for constituents – their goal is to have 1,000 new people sign up. They are attempting to find at least one constituent in every legislative district in the country so they can better advocate with congressional leaders. Sign up to help them <u>here</u> and share it with your friends and family.



#### Many Shades of ALS Team

Team member Maceo made a guest appearance on Lorri Carey's podcast "I'm Dying to Tell You." They discussed "what you want to know, but were afraid to ask" about all things ALS. Maceo always brings honesty and humor to difficult conversations, so you won't want to miss this! Check it out here.



#### Veterans Team

This team is hosting the next installment of Ask Me Anything ALS on Tuesday, May 24th! An amazing panel of team members will be joined by a member of our ALS Support Team to answer your questions and connect you with resources. Sign up to join them <u>here</u>!



### **Community Spotlight: Paul Carey**

Paul's amazing mom Lorri is an all-star advocate living with ALS. This year for Mother's Day, Paul wrote a beautiful story of their ALS experience together. He describes his mom as "the chart-climbing podcaster, the advocate-of-the-year, and the unmatched goodnight-texter." Read Paul's story <u>here</u>, and check out Lorri's podcast <u>here</u>!

## WHAT'S COMING UP?

#### Lou Gehrig Day!

It's almost time!! On June 2nd and 3rd, Major League Baseball teams and stadiums across the country will honor and celebrate Lou Gehrig Day. ALS

advocates are hosting over a dozen events countrywide at both Major League and Minor League games, as well as watch parties at local breweries and bars. See if there's an event happening near you – and if not, make one! **Register** 

#### Ask Me Anything ALS - Veterans

Navigating the systems and many resources out there can be challenging and overwhelming. There are unique benefits available to veterans with ALS and their loved ones and the sooner you understand those benefits and how to access them, the better you can plan for your changing needs. The I AM ALS Veterans Community Team is ready to answer your questions and discuss how ALS uniquely impacts veterans. **Register** 

#### Immunity, Virus, and the Role of Inflammation in ALS Webinar

This webinar from Everything ALS will be hosted by Matthew S. Miller PhD, Associate Professor of Biochemistry & Biomedical Sciences at McMaster University.

**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.



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