# IAM ALS



## GET IN. WE'RE ENDING ALS

"When you live with a terminal disease, one thing that never ceases to amaze is the resiliency of the human spirit even as you realize the fragility of the human body." - Brian Wallach, I AM ALS Co-Founder

#### What We're Up To

President Biden signed the ALS SSDI Technical Fix bill (S.579) that ensures those stuck in the waiting period for social security disability benefits will start receiving benefits now. This happened because advocates and congressional ALS champions came together to ensure financial dignity for those living with ALS. Thank you for helping us get this done.

#### Share Your Story Are you a woman who was diagnosed with ALS under the age of 35? Share your story here.

I'M READY

## COMMUNITY UPDATES



#### Clinical Trials Team

The team just rated Apellis Pharmaceutical's phase 2 trial testing pegcetacoplan in patients with sporadic ALS. Read more about the <u>trial and rating here</u>.



Community Outreach Team Team members met with nursing students this week to educate them on the ALS experience. Does your organization want to host a panel of people impacted by ALS? If so, <u>click here</u>.



Legislative Affairs Team

In just the first three months of 2021, the team has contacted more than 325 representatives and senators. Good work, team!



Veterans Affairs Team The team will be presenting on its incredible work at the <u>Paralyzed Veterans of America Health Summit and Expo</u> in Dallas, TX in August!



Meet Morgan Geniviva: <u>Morgan</u> is new to I AM ALS, but she is making waves. She is one of the incredible forces behind the <u>Community</u> <u>Outreach TeamÕs efforts</u> to educate students about the ALS experience. We are so grateful that Morgan is on our team!

### WHAT'S COMING UP?

I AM ALS Social Hour

Every week those impacted by ALS get together to laugh, cry, celebrate and connect with one another during our social hour. Join us on Tuesday at 4 p.m. ET! Register

ALS Learning Series: Grief and Loss in Children and Youth in Families Living with ALS

Join a conversation with Melinda Kavanaugh, PhD, MSW, LCSW on how children cope with grief and loss. Families will learn how



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.



1200 Pennslyvania Ave NW, #14135 Washington, DC 20044