IAM ALS



GET IN. WE'RE CURING ALS

"I dream of a world in which no one dies from a 'rare' disease. Better yet I'm dedicating all of my days to making that dream real. " - Brian Wallach, Co-Founder of I AM ALS

What's Up With Us

The bill to waive the five-month waiting period for social security disability insurance for those with ALS has passed in the Senate and the House! CELEBRATE!

You may be wondering: Who is that Bitmoji? It's Michael, I AM ALS' community lead organizer!

Tell Me Something

How do you like the newsletter? Is it too long? Too short? Is something missing? Take 60 seconds to let us know by clicking below!

> SHARE YOUR THOUGHTS

COMMUNITY UPDATES



Clinical Trials Team

As always, we are impressed with the Clinical Trials TeamÕs hard work. Next on the agenda is deciding what trials to rate using the patient- and caregiver-created <u>PaCTD rating system</u>!



Legislative Affairs Team

SSDI (H.R.1407/S.578) passed the House and the Senate! The Legislative Affairs Team wants to take a moment to thank all advocates out there who reached out to their elected officials and made this happen! The team encourages basking in your success, then taking that energy and directing it into passing <u>ACT for ALS</u>!



Thank You Squad

Wow! The support poured in on Giving Tuesday. And the sensational Thank You Squad, which writes a personal handwritten thank you note to each individual donor, went into full action mode to quickly create and implement a plan to ensure everyone feels the love. Our hearts are forever bursting with gratitude for this incredible squad!



Veterans Affairs Team

This week the team rolled out its veteran's health care gap analysis survey. This survey will help them continue their mission of improving veterans' health care. Help them by spreading this survey far and wide.



Huge shout out to Deb, the Legislative Affairs Team scribe! She is a relentless advocate for ALS. Without her energy, commitment and ability to build relationships with 30,000 legislators (not really É it just feels like that) we wouldnÕt be where we are today. THANK YOU, DEB!

WHAT'S COMING UP? DECEMBER 14-20

I AM ALS Social Hour

Third week going strong! Many from the community have joined our team during our weekly social hour and we have been loving it. We hope you can make it to our next one on Tuesday. <u>Register</u>

NEALS Results of the REFALS Study

Join Dr. Merit Cudkowicz from the Sean M. Healey & AMG Center at Mass General Hospital on Tuesday as she reviews the results of the REFALS trial evaluating the effect of oral levosimendan (ODM-109) on respiratory function in people with ALS. <u>Register</u>

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 <u>iamals.org</u>.



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