



Get In, We're Ending ALS

What We're Up To

We are beyond excited to welcome Andrea Goodman as the new CEO of I AM ALS!! Andrea is an experienced public health leader with a passion for driving equity, healthcare efficiency, and patient empowerment. She most recently served as the Senior Vice President of Patient Support & Research Strategy at the Colorectal Cancer Alliance where she oversaw the patient service and research portfolios. Andrea's first day will be this Monday, April 10th. Learn more about her here: <https://iamals.org/updates/i-am-als-appoints-andrea-goodman-as-chief-executive-officer/>

We want to hear from you!

How do you feel about I AM ALS' emails? Our social media? Our website? We want to know! Your feedback will help us shape our communications and marketing priorities going forward.

TAKE THE SURVEY

COMMUNITY UPDATES



Clinical Trials Team

This awesome group of people is responsible for keeping ALS Signal up to date, alongside other incredible ALS advocacy. If you are interested in joining these changemakers, learn more about what they do and sign up here: <https://iamals.org/action/join-an-i-am-als-community-team/>



Community Outreach Team

A team of amazing advocates is planning an ALS Art Show! This project will include an online gallery and a virtual gallery opening event. The show will feature art created by people living with ALS and by those who have passed from ALS. The call for artists will be going out next week, so stay tuned!



Legislative Affairs Team

This team is amazing and continues working tirelessly to ensure that Congress fully funds ACT for ALS with a strong focus on securing \$75 million for Expanded Access Research programs. This team is also working to grow the Congressional ALS caucuses. The Senate Caucus is about to relaunch and we need your help to help grow its size and get more Senators to join! Click here: <https://iamals.org/action/build-the-als-caucus/>



Lou Gehrig Day Team

Come join our spirited team and help organize events before, during, and after games! We are looking for team leads for the Chicago White Sox, Philadelphia Phillies, New York Yankees, Oakland Athletics, St. Louis Cardinals, Toronto Blue Jays, and Minnesota Twins. Sign up here and get into the games! <https://iamals.org/join-us-for-lou-gehrig-day-2023/>



Veterans Team

The Veterans Team has been kicking serious booty! They have met with numerous Congressional members that sit on the House & Senate Veteran committees to advocate for doubling of CDMRP for ALS research and passing the Elizabeth Dole Home Care Act. This team is phenomenal!! To help pass the Elizabeth Dole Home Care Act, click here: <https://iamals.org/action/elizabeth-dole-home-care-h-r-542-s-141/>



Young Adult Team

We're looking to grow our Young Adult Team! If you are 18-29 years old and looking to find and use your voice in the ALS space, this is the team for you. This small but mighty team features passionate and caring advocates who want to connect with other young adults in the ALS community. Join us if you'd like to be a part of this unique team!

<https://iamals.org/action/youngadultteam/>

The logo for 'Community Support Corner' features the text in a bold, yellow, sans-serif font. The words are stacked vertically: 'COMMUNITY' at the top, 'SUPPORT' in the middle, and 'CORNER' at the bottom. The text is set against a light blue background with a pattern of small white dots in the corners.

COMMUNITY SUPPORT CORNER

Memories Live uses the power of your story to create a legacy movie that documents your stories, family history, images, and advice to be treasured by your loved ones. Films are created for individuals with life-limiting illnesses at no cost to them. Learn more about how their process works by visiting **their website**, or by reaching out to them directly by emailing **kerry.glass@memorieslive.org** or calling 646-245-1698.



Community Spotlight: Her ALS Story
Her ALS Story is an amazing place for women diagnosed with ALS under the age of 35 to find support, community, and camaraderie. This past week community members came together for an incredible Ask Me Anything ALS event focused on Women Living with ALS, in partnership with Her ALS Story. It was a raw and powerful conversation, and a great way to close out Women's History Month. If you missed the event, you can watch the full recording here: **<https://www.youtube.com/watch?v=b8IEGfyWCto&t=213s>**

WHAT'S COMING UP?

Expanded Access 101: Empowerment Through Education

Together with the NYU Grossman School of Medicine, CUPA (Working Group on Compassionate Use and Preapproval Access) is providing this crash course on Expanded Access on Wednesday April 12th at 12pm ET. This webinar will provide a stakeholder-focused introduction to the often misunderstood topic of expanded access, where a diverse panel will

unpack the regulatory, legal, medical, and ethical aspects of this important regulatory pathway.

Register: <https://www.eventbrite.com/e/expanded-access-101-empowerment-through-education-tickets-596988166677>

Talk with Prof. Guillaume Hautbergue for the Genetic ALS & FTD Community

End the Legacy Genetic ALS & FTD presents a webinar for the genetic ALS & FTD community from Prof. Guillaume Hautbergue on Tuesday, April 11 at 12pm ET. Prof. Hautbergue is an expert in RNA biology and he and his lab recently published on a peptide that was able to prevent the death of nerve cells and protect them from degeneration in C9orf72-ALS/FTD animal models. He also recently reported a gene therapy approach targeting the same biological process.

Register: <https://www.eventbrite.com/e/talk-with-prof-guillaume-hautbergue-for-the-genetic-als-ftd-community-tickets-598720879267>

Les Turner ALS Learning Series: ALS & Exercise

Many people living with ALS struggle to understand whether it is okay to exercise, what kind of exercise is most beneficial, and whether exercise slows disease progression. On Thursday April 20th at 1pm ET, Hannah Redd PT, DPT, NCS, at Shirley Ryan AbilityLab, will discuss the benefits of exercise among people living with ALS along with providing insight into appropriate exercises and signs of overworking. A Q&A will follow the presentation.

Register:

<https://register.gotowebinar.com/register/3042676758300304988>

[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.

IAM ALS



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