



Get In. We're Ending ALS

What We're Up To:

The FDA's Advisory Committee meeting regarding NurOwn is drawing closer (September 27th), and the period for public comment is now open. This is your opportunity to make a case to the advisory committee about why NurOwn matters. We've created a guide that will help you write and submit testimony and make it the best it can be. Check it out here:

<https://iamals.org/updates/guide-to-submitting-written-testimony-to-the-fda-about-nuown/>.

Note: the comment period will close on **September 20th**.

We Want Your Feedback

I AM ALS is conducting a brief but important survey to gain insights on how to best serve and organize the ALS community. Please help by filling this out by next Friday (8/25) as we continuously improve!

TAKE THE SURVEY

COMMUNITY UPDATES



Community Outreach Team

Do you know a group, organization, or club that could benefit from learning about ALS? Then you may be interested in a Tim Lowrey ALS Panel! This panel series consists of people living with and impacted by ALS who seek to educate others about ALS and their experiences. The panels include a brief introduction to ALS, a panel discussion wherein

panelists share their experiences, and a Q&A. If you know a group who could benefit from a panel, you can request one here:

<https://iamals.org/action/request-a-panel/>



Familial ALS Team

Thinking about getting genetic testing for ALS? Then join people living with or impacted by familial and sporadic ALS in this session of Ask Me Anything ALS: Genetic Testing. Sign up to join them, plus a genetic counselor, on August 23rd: <https://iamals.org/action/ask-me-anything-als-genetic-testing/>



Legislative Affairs Team

Our amazing Legislative Team continues their work to thank members of Congress who were part of the 118th House which funded ACT for ALS at \$75 million for Expanded Access programs. They are also asking them to advocate for keeping ALS research at \$40 million for the CDMRP. Want to make a difference? Come join the team!

<https://iamals.org/action/legislative-affairs-team/>



The Write Stuff

More good things are happening on the Write Stuff Team's blog! Visit the Forum page and check out the recent writings as well as the community member discussions. <https://www.alsthewritestuff.com/forum>



Veterans Team

Improving access to home health care is at the top of the agenda for the Veterans team. That's why they are advocating for the passage of the Elizabeth Dole Home Care Act. Read more here:

<https://iamals.org/action/elizabeth-dole-home-care-h-r-542-s-141/>



Young Adult Team

The Young Adult Team just completed their first social media campaign to bring awareness to the young adult ALS experience. The campaign ran for a week and included a series of tweets that captured the full experience-from funny to moving. You can join the Young Adult Team and help with projects like this here:

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

Are you a Veteran living with ALS who is looking to connect with peers? The I AM

The logo for 'Community Support Corner' is located in the top left corner. It features the words 'COMMUNITY', 'SUPPORT', and 'CORNER' stacked vertically in a bold, orange, sans-serif font. The text is set against a light blue background with a pattern of small orange dots in the corners.

COMMUNITY SUPPORT CORNER

ALS support group for Veterans living with ALS meets on the fourth Wednesday of every month from 12-1pm CST. This virtual support group offers a safe space for people with similar experiences to share and receive support. Sign up here: <https://iamals.org/action/join-a-support-group/>

In Memoriam: Gregory Martin Hirsch

It is with great sadness that we share **Gregory Martin Hirsch**'s passing from ALS. Greg was an incredible ALS and cancer advocate and contributed greatly to his hometown of Savannah, GA. He will be greatly missed. In his memory, we say, "Go Bulldogs!"

WHAT'S COMING UP?

August Social Hour

School may be starting again, but we still plan to have some summer fun! Join us for our August Social Hour on August 30th from 6-7pm ET. As a refresher, social hour is an hour-long meeting where members of the community can come to hang out, chat, and spend time together.

[Register](#)

Amyotrophic Lateral Sclerosis: Accelerating Treatments and Improving Quality of Life - Workshop 2

Part two of the National Academies of Science, Engineering and Medicine (NASEM)'s webinar series on ALS will take place on August 23rd at 12pm ET. This session will allow people living with ALS, caregivers, and individuals at genetic risk of developing ALS the chance to engage with the committee on various topics related to their quality of life, health, and well-being.

[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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