



### ALS Association Applauds Amylyx's AMX0035 Announcement, Urges Swift FDA Approval

Following Amylyx's announcement that it intends to submit a New Drug Application (NDA) for AMX0035, The ALS Association urges the Food and Drug Administration to approve the treatment for all people with ALS as soon as possible.

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## care corner

### Comprehension with ALS



Due to changes in muscle tone, muscle strength, and respiratory status, communicating with ALS can become more difficult. Dr. Julie Stierwalt and Dr. Rene Utianski, Speech Language Pathologists with Mayo Clinic, have developed some techniques that the speaker and listener can use to improve comprehension during communication.

Check out this [one-pager](#) for techniques and strategies.

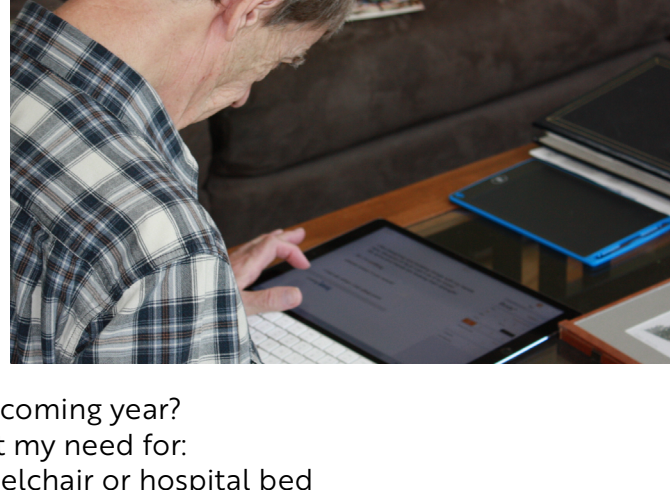
### Medicare Open Enrollment Is Just Around The Corner!

October 15 to December 7 is the time when all Medicare beneficiaries can change their Medicare health plans and prescription drug coverage for the following year to better meet their needs. We highly recommend discussing your health insurance options with an insurance counselor. Insurance counseling is a free service available in each state that provides unbiased information to Medicare enrollees about the plans available in their state.

In order to get the best guidance possible, please consider the answers to the following questions:

- What medications do I currently take/plan to take in the coming year?
- How might my ALS progression over the next year impact my need for:
  - Durable medical equipment, such as a power wheelchair or hospital bed
  - A communication device (a machine that helps an individual verbally communicate)
  - Office visits to an ALS clinic or other physicians

To find your State's Health Insurance Counseling Program, click [here](#).



### The Benefits of Physical Therapy for People Living with ALS



October is National Physical Therapy Month, a time to raise awareness of the key role that physical therapists play in helping people improve mobility, find relief from pain, and live healthier, more physically able lives.

### ALS Association to CMS: We Urge You to Listen to People Living with ALS



Unlike most Medicare recipients who need extensive home care and rehabilitative services, people with ALS do not improve, and the intensity of their service needs increase over time. That means standard Medicare cost control approaches don't work well.

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### Upcoming Care Services Programs

October 14	<b>Northern MN Support Group (Virtual Meeting)</b>	October 20	<b>Family Caregiver Support Group (Virtual Meeting)</b>
October 14	<b>Family Caregiver Support Group (Virtual Meeting)</b>	October 26	<b>SD and Southern MN Support Group (Virtual Meeting)</b>
October 19	<b>ND and Central MN Support Group (Virtual Meeting)</b>	November 2	<b>Education Hour (Virtual Meeting)</b>
October 19	<b>Young Adult Hangout (Virtual Meeting)</b>	November 3	<b>Minneapolis/St. Paul Metro Area Support Group (Virtual Meeting)</b>

Midweek Meditation - Every Wednesday at 11:00 AM (CT)

## research updates

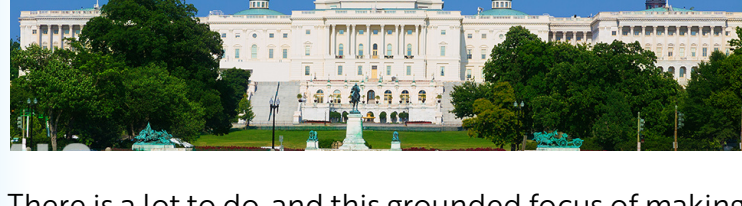
### Q&A: How Amylyx NDA Announcement Moves the Fight for Access to AMX0035 Forward



After Amylyx's announced that it intends to file a new drug application for AMX0035, The ALS Association immediately called on the U.S. Food and Drug Administration to approve the treatment for all people with ALS as soon as possible. Connecting ALS talked to the team at Amylyx to learn about the path ahead for access to AMX0035.

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### AMX0035 Proves Advocacy from ALS Community Can Impact Drug Development



There is a lot to do, and this grounded focus of making ALS livable helps us hold everyone—ourselves, the FDA, and the research community—accountable to real impacts on real people with ALS and the time it takes to deliver those impacts. This week has been a big step forward for the ALS community, and we will continue urgently working to keep the momentum going.

### Here's Why the ALS Registry and Biorepository Matters



The National ALS Registry and Biorepository was created back in 2007 to help understand how prevalent ALS is, who is developing ALS, and what the possible causes are. Its mission is also to help support researchers in discovering treatments and cures and in preventing ALS.

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## hey volunteers

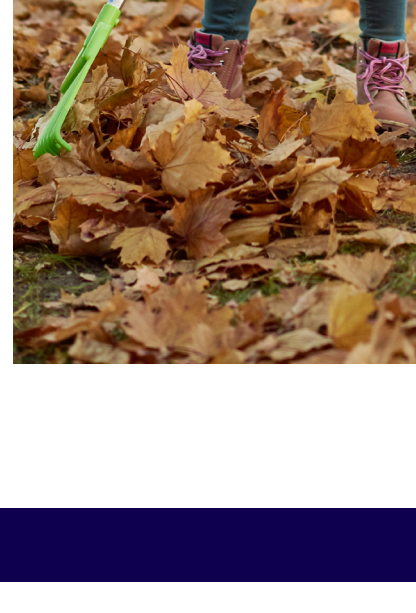
### Want to Connect Directly with Someone? Become a Family Assistance Volunteer

Through this program, volunteers are connected with families affected by ALS to help with everyday tasks or provide companionship.

With assistance, families report that their stress level is lowered knowing certain tasks will get done on a regular basis. The person living with ALS may not be able to physically complete the tasks and their caregiver may not have the time or energy. Additionally, most volunteers and families develop close relationships as time progresses.

The requests for assistance vary by task, frequency, and length and you can choose what works best based on your interests and availability. The Family Assistance Program has now reopened to both indoor and outdoor activities, with COVID-19 safety protocols in place.

If you have any questions about volunteering, the volunteer positions available, or the application process, please call 612-455-6052 or email [jenna@alsmn.org](mailto:jenna@alsmn.org). You can also visit our [VolunteerMatch](#) page to view current requests for assistance.



### Help Wanted!

We have several open family assistance requests right now in Minnesota. Could one be near you? Current needs by city include:

- Cushing: cleaning
- Eagan: scrubbing tub/shower (monthly)
- Kasota: groceries, laundry, decluttering/organizing
- Princeton: weeding, edging
- St. James: mowing (seasonal), shoveling sidewalk (seasonal), basic technology assistance

If you live in or near any of these cities, we'd love to chat with you about how you can help support one of these families. Please contact Jenna (612-455-6052 or [jenna@alsmn.org](mailto:jenna@alsmn.org)) for more information.

## CARE CONNECTION

Did you know that The ALS Association has its own online calendar to also help coordinate your household needs? [ALS Care Connection](#) is a private online tool that can be used to support your family by organizing volunteers to take care of a variety of tasks. Visit our [website](#) to learn more about this tool and its features, including a recent webinar and step-by-step guide to getting started.

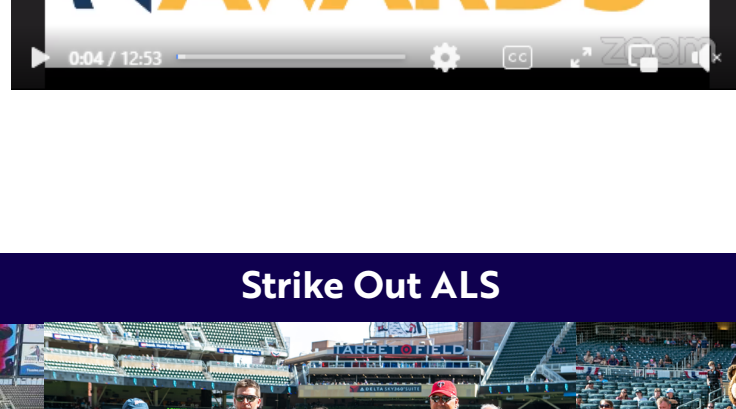
## event news

### 2021 Walk to Defeat ALS A Huge Success

That's a wrap on the 2021 Walk to Defeat ALS season! Even though we were unable to gather as originally intended, we were energized by your photos and feeling the excitement of the Walk. From Sioux Falls to Bismarck, Rochester to St. Cloud and countless other communities, we have seen hundreds of photos and videos of people showing support.

Despite all the changes in Walk Day plans, it did not get in the way of fundraising efforts. Today our community of supporters has raised **\$911,000** and counting across all 3 states' Walks!

We recently hosted a Walk Awards show recognizing some of this year's most creative, engaged, and impactful participants and teams. Check out the winners [here](#):



### Strike Out ALS



Once again this year, our Chapter partnered with the Minnesota Twins to Strike Out ALS with every home strikeout pitched by the Twins. On Sunday, September 26th, the Twins hosted members of our ALS community at Target Field to celebrate this season's efforts. Our friends at Carrier, joined by Twins legend Kent Hrbek, presented our executive director, Jennifer Hjelle, with a generous \$10,000 donation in support of this year's Strike Out ALS campaign.

Joining the group on the field was Twins fan Lynn, who is living with ALS and has spearheaded her own #StrikeOutALS fundraising efforts, as well as Shirley, who is living with ALS and was in for a very special surprise of her own. Thanks to our partners from the Permobil Foundation, LiveLikeLou Foundation, Phi Delta Theta Fraternity and Reliable Medical, we helped surprise Shirley with a custom Twins-themed Permobil power wheelchair that will enhance her mobility and independence as she lives with ALS.

Watch the vide of this powerful moment [here](#). Through MLB's annual Lou Gehrig Day tradition and the Twins' Strike Out ALS efforts, opportunities like these help us spread awareness, get closer to a cure, and support people like Shirley and Lynn who are living with ALS.

### Save the NEW Date for the 19th Annual Light the Journey Gala



We're excited to announce the move of the Light the Journey Gala to springtime. With heightened precautions around COVID-19, the move of the Gala to spring gives us the best chance to host the event in a way that honors the community we serve and the incredible network of supporters that make our mission possible.

After a wonderful winter, join us on April 9th, 2022 at the Radisson Blu Mall of America for an evening of hope spotlighting Gayle and her family's journey with ALS.