



**House Subcommittee Unanimously Approves ACT for ALS**

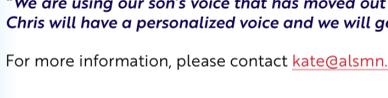
Accelerating Access to Critical Therapies (ACT) for ALS (H.R. 3537) was approved by a unanimous vote on Thursday, November 4 in the House Energy and Commerce Subcommittee on Health. Thanks to everyone within the ALS community who has advocated for passage and who has worked on Capitol Hill to help make this important step happen. The strong bipartisan support for this bill means smooth sailing as the bill goes to the full House Energy and Commerce Committee and then the full House for approval.

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**care corner**

**Give The Gift of Voice Banking**

In this season of gift-giving and looking forward to what a new year holds, consider voice banking as a personalized gift you give yourself and your loved ones. Preserving one's natural voice through Voice Banking or Message Banking may allow a person to have a unique, personalized voice file that mimics one's natural speaking voice and may allow one to preserve signature messages or "isms" so they may always be communicated exactly how you wish them to be heard.



Your ALS clinic or ALS chapter will encourage you to do this early on after your diagnosis, while your voice is clear and easy to hear. If for some reason that isn't possible, you can have a family member or friend whose voice is either similar to yours, or just one that you particularly like, donate their voice on your behalf. They would go through the recording process, and their voice file will be downloaded into whatever device you use for communication. Many families choose this option, including Chris, who currently lives with ALS. Here's what his wife Jessica had to say:

*"We are using our son's voice that has moved out of the house already. It will be a double bonus because Chris will have a personalized voice and we will get to hear our son's voice every day."*

For more information, please contact [kate@alsmn.org](mailto:kate@alsmn.org) or [corrie@alsmn.org](mailto:corrie@alsmn.org), or visit [this page](#).

**Welcome to the Chapter, Kate Nilson!**

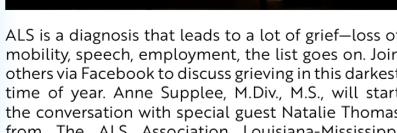
We are thrilled to share that on November 22, 2021, Kate Nilson, Speech Language Pathologist, joined our team as our newest Care Services Coordinator.



Kate comes with over 13 years of experience as a Speech Language Pathologist and a passion for Augmentative-Alternative Communication. Kate also has experience working in higher education with a strong passion for teaching current and future SLPs.

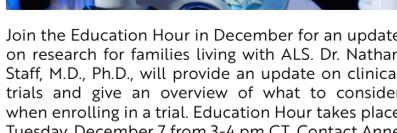
She has worked at the M Health Fairview ALS Clinic for the past five years and will continue that role while also supporting the Hrbek-Sing Communication program and other Care Services programs at the Chapter. Welcome, Kate!

**Grief In The Darkest Time of the Year**



ALS is a diagnosis that leads to a lot of grief—loss of mobility, speech, employment, the list goes on. Join others via Facebook to discuss grieving in this darkest time of year. Anne Supplee, M.Div., M.S., will start the conversation with special guest Natalie Thomas from The ALS Association Louisiana-Mississippi Chapter on a Facebook Live and welcome reflections from others in the ALS community. Tune in on our Facebook page on Monday, December 13 at 4pm CT.

**Join Education Hour for a Research Update**

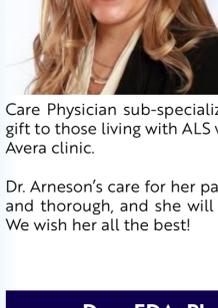


Join the Education Hour in December for an update on research for families living with ALS. Dr. Nathan Staff, M.D., Ph.D., will provide an update on clinical trials and give an overview of what to consider when enrolling in a trial. Education Hour takes place Tuesday, December 7 from 3-4 pm CT. Contact Anne ([anne@alsmn.org](mailto:anne@alsmn.org)) to receive the Zoom link. The session will be recorded for those who can't attend live.

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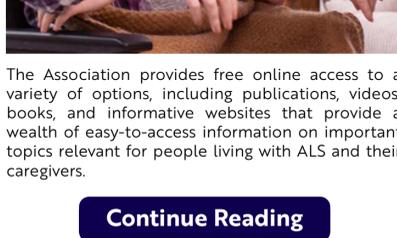
**Clinic Director Dr. Arneson Leaving Avera ALS Clinic**



The Avera ALS Clinic, a Recognized treatment center, in Sioux Falls will be saying goodbye to Dr. Francine Arneson at the end of this year. Dr. Arneson was director of the ALS multidisciplinary clinic for 3 years. Her training as a Palliative Care Physician sub-specializing in Neurology was a gift to those living with ALS who received care at the Avera clinic.

Dr. Arneson's care for her patients was always gentle and thorough, and she will be missed at the clinic. We wish her all the best!

**Finding Critical Resources for ALS Caregivers**



The Association provides free online access to a variety of options, including publications, videos, books, and informative websites that provide a wealth of easy-to-access information on important topics relevant for people living with ALS and their caregivers.

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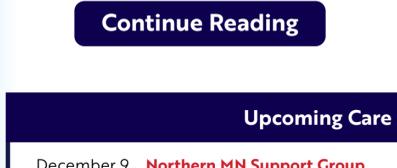
**Dear FDA: Please Grant Priority Review to AMX0035 and Approve It**



We asked the FDA to treat the approval review process of AMX0035 with urgency. Specifically, we sent a letter to the FDA asking the agency to conduct a Priority Review of Amylyx's New Drug Application (NDA) for AMX0035 and then approve it. The Priority Review is an expedited review process, as opposed to the Standard Review process, which can take upwards of a year after the agency accepts submission of the NDA.

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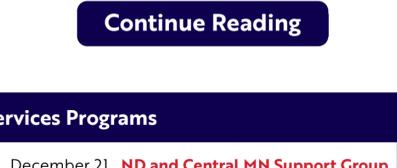
**Enjoying the Holidays, One Delicious Meal at a Time**



Holiday celebrations are times of fun, fellowship and of course, food. And, while the holidays are meant to be enjoyed, they can also be a tremendous stressor for people living with ALS and their families. Learn tips to help enjoy the holidays and delicious easy chew, easy swallow recipes the whole family will enjoy.

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**Researcher Spotlight: Caroline McHutchison**



Milton Safenowitz Postdoctoral Fellow

We spoke with Dr. Caroline McHutchison, a postdoctoral fellow from the University of Edinburgh, to learn more about her research focused on examining the presence, onset, and evolution of cognitive and behavioral symptoms, relative to motor symptom onset and diagnosis of ALS.

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**Upcoming Care Services Programs**

December 9	<b>Northern MN Support Group (Virtual Meeting)</b>	December 21	<b>ND and Central MN Support Group (Virtual Meeting)</b>
December 9	<b>Family Caregiver Support Group (Virtual Meeting)</b>	January 4	<b>Education Hour (Virtual Meeting)</b>
December 15	<b>Family Caregiver Support Group (Virtual Meeting)</b>	January 5	<b>Minneapolis/St. Paul Metro Area Support Group (Virtual Meeting)</b>
December 21	<b>Young Adult Hangout (Virtual Meeting)</b>		

Please note: The South Dakota and Southern Minnesota support group will not meet in Dec. 2021. This support group will resume in Jan. 2022.

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

**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.

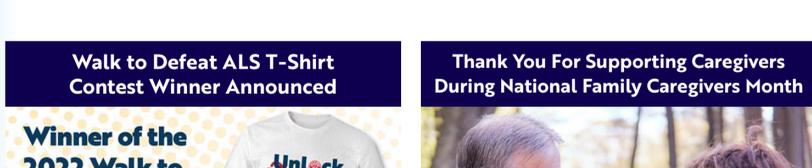


With assistance, families report that their stress level is lowered knowing certain tasks will get done on a regular basis. The person living with ALS may not be able to physically complete the tasks and their caregiver may not have the time or energy. Additionally, most volunteers and families develop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

**Find Support Through The 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.

**community news**

**Your Gift to Research Can Be Doubled This Month!**

**Help meet the needs of the ALS community this giving season**

Thank you for the generous contributions you have made to our Chapter throughout the year. As 2021 draws to a close, your support can help us finish our year strong and ensure the care we provide to the ALS community is the best it can possibly be.

If you're interested in contributing to ALS research, your gift can be doubled this month. Thanks to the **Nemitz-Waite Family Research Challenge Match**, honoring Robert Nemitz, who passed away from ALS in 2013, research gifts made in December will be doubled, **up to \$25,000**.

To make a year-end, tax-deductible gift to Chapter programs and services or ALS research, please visit our [online donation page](#). Thank you for being such a valuable partner in the fight against ALS!

[Give Now](#)

**Walk to Defeat ALS T-Shirt Contest Winner Announced**

**Winner of the 2022 Walk to Defeat ALS Nationwide T-Shirt Contest!**



Thank you to everyone who participated in our nationwide t-shirt design contest! The winning design, created by Anne Fahey, will be featured on the 2022 Walk to Defeat ALS t-shirts.

Anne is a graphic designer in Princeton, New Jersey, who was diagnosed in 2020 with bulbar onset ALS. She is grateful for the dedicated support and resources of the entire ALS community, especially her local chapters of The ALS Association.

Like the Walk to Defeat ALS Facebook page to be the first to hear details about the 2022 Walks!

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**Thank You For Supporting Caregivers During National Family Caregivers Month**



Thank you for making **National Family Caregivers Month** a huge success. Your donations and words of encouragement throughout November made a positive difference for individuals living with ALS and their caregivers throughout our region.

Our Chapter delivered over 300 Caregiver Kits to let caregivers know how important they are and over \$45,000 in donations were inspired during the month to continue supporting the caregiving journey.

*"Thank you for the caregiver kit! There is already so much support coming from all of you at The ALS Association—and it is so appreciated. I know hard days are on the horizon ... Thank you for building our relationship along the way."*

-Local caregiver

**Thank You to Our Walk Sponsors**

We'd like to extend a special thank you to the team at Reliable Medical Supply for their steadfast support of our work and the ALS community. Reliable Medical houses the Chapter's largest durable medical equipment loan pool, with over 900 pieces on-site at any given time. From its three locations in our service area, Reliable Medical helps our Chapter deliver and distribute thousands of pieces of DME to those we serve, providing everything from bath safety equipment to electric scooters. Reliable Medical is also a supporter of our Chapter's events, and this year marks the company's 15th year as sponsors of the Walk to Defeat ALS. Reliable Medical continues its tradition of fundraising in support of our Chapter by hosting creative fundraisers, organizing several Walk Teams, and being an advocate of our work. Thank you, Reliable Medical, for your continued support of our community and impact on our work!



We'd also like to thank Old National Bank, another one of our dedicated partners. Old National Bank began its partnership with the Chapter in 2018 at the Empower event to support the Walk to Defeat ALS. This year they elevated that partnership to Momentum, creating an even bigger impact for the ALS community. When a dedicated employee's family member was diagnosed with ALS, Old National wanted to do more. The company formed a Walk Team and proceeded to raise over \$1,700 in support of the Chapter, saying "It is wonderful to be able to support not only our employee but others who are living with ALS." Thank you for your dedication to defeating ALS, Old National Bank!