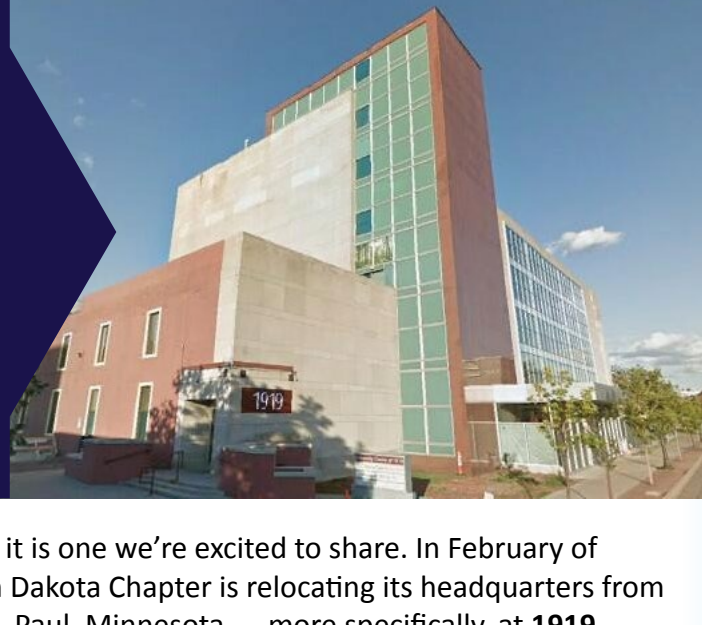
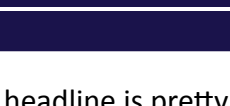




WE'RE MOVING!

new headquarters opening soon



The headline is pretty straightforward but the story behind it is one we're excited to share. In February of 2019, The ALS Association Minnesota, North Dakota, South Dakota Chapter is relocating its headquarters from downtown Minneapolis to the Midway neighborhood of St. Paul, Minnesota — more specifically, at **1919 University Centre**, near the corner of University and Prior. The current office space at Union Plaza in the North Loop of Minneapolis has served us well for a number of years, but for various reasons we've been unable to mold it into the welcoming environment we originally envisioned.

Our Chapter is growing, and our new space will provide more flexibility for expanded programming to address the evolving needs of the ALS community. But the primary reason for this move can be boiled down to one word: **accessibility**.

The new offices will be an upgrade in nearly every way. The building itself (pictured above) is located directly on the Green Line of the Twin Cities' light rail transit system and also features ample accessible parking. The 10,000 sq. ft. suite, which is currently undergoing a custom buildout, is located on the first floor and will be our operational hub as we explore new ways to serve individuals and families across three states.

Perhaps the most exciting element of the new space will be our 2,000 sq. ft. **Connectivity Center**, which will house emerging technologies related to ALS care. Made possible from a generous grant from Margaret A. Cargill Philanthropies, this space will allow us to host trainings, webinars, equipment demonstrations, support groups and more from a highly modular setting. We'll be unveiling more details after the dust settles, but expect to hear about video conferencing, educational podcasts, video tutorials, and telehealth collaborations in the near future.

Our staff and Board of Directors are simply buzzing about the potential and we genuinely believe this will be a transformational moment for ALS care and support in our region. Whether you live in Minot, Sioux Falls, or Duluth, this move will foster an even stronger connection between The ALS Association and the people we serve.

We would also like to acknowledge that this kind of move would not be possible without your generous support of our Chapter. The faith you demonstrate in our efforts motivates us to work even harder on your behalf, and we look forward to having you alongside us as we embark on this journey. If you have any questions about the move and our future plans at the new Chapter headquarters, feel free to contact me directly (612.672.0484 / jenniferhjelle@alsmn.org). And if you'd like to make a contribution in support of this important effort, you can **donate online today** or call for additional details.

I can't wait to welcome you into our new space!

Sincerely,

Jennifer Hjelle

Jennifer Hjelle
Executive Director
The ALS Association MN/ND/SD Chapter



READER SURVEY

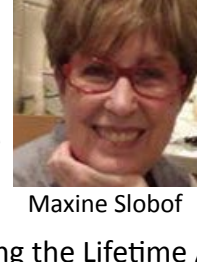


We want your input! As we prepare to open our new **Connectivity Center**, we'd like to hear from you on how best to utilize the space in the future.

care corner

Changes at the ALS Center of Excellence at Hennepin Healthcare

Maxine Slobof, the speech-language pathologist at the ALS Center of Excellence at Hennepin Healthcare is leaving her position in early December after almost two decades of service. Maxine has dedicated her career to helping those with speech-language, cognitive and swallowing disorders/difficulties. Her expertise has been invaluable, not only to the people with ALS but also to ALS physicians regarding the ALS diagnostic process. Maxine is well-respected by her peers, as well as the ALS team at Hennepin Healthcare. She has been involved in ALS research and has received many awards from the MN Speech-Language-Hearing Association, including the Lifetime Achievement Award in 2015, as well being named as a Fellow at the American Speech-Language-Hearing Association (ASHA) in 2008. This is the highest form of recognition given by ASHA of an individual's accomplishments and is a public declaration of outstanding professional achievements. Maxine's expertise is something to behold but it pales in comparison to her warm and caring heart. On behalf of The ALS Association, thank you for your 20 years of service to the ALS community.



Maxine Slobof Kim Churness

Maxine is leaving the ALS clinic in the capable hands of Kim Churness, another speech-language pathologist at Hennepin Healthcare. Like Maxine, Kim has her Master's degree in Speech-Language Pathology. Kim completed her clinical fellowship training at South Texas Veterans Hospital in San Antonio where she worked with individuals with ALS on their communication and swallowing needs. Kim works with the acute inpatient (adult) population with a focus on speech-language, cognitive-linguistic, swallowing and alternative communication needs. She also provides services for patients in the Mild Traumatic Brain Injury (TBI) Clinic at Hennepin Healthcare. Welcome, Kim!

Young Adult Support Group

Do you have a parent with ALS? do you want to be connected to other young adults in a similar situation?

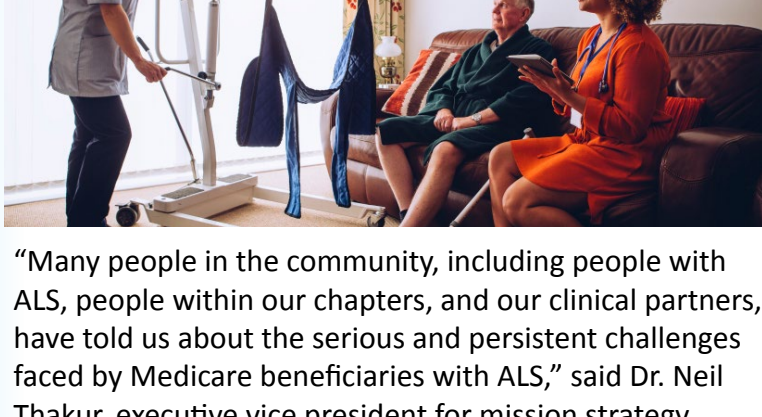
Join us for our monthly Google Hangout.

Third Tuesday of the Month
7-8 PM CST

Contact Anne Supplee to Join
anne@alsmn.org | 888.672.0484



People with ALS Should Have Access to the Medicare Home Health Benefits They Deserve



"Many people in the community, including people with ALS, people within our chapters, and our clinical partners, have told us about the serious and persistent challenges faced by Medicare beneficiaries with ALS," said Dr. Neil Thakur, executive vice president for mission strategy at The ALS Association. "Many such beneficiaries, despite being fully qualified, are turned down for the home health benefits they deserve. Other beneficiaries are able to receive Medicare home health but deal with inadequate hours of service and inappropriate termination from care." **Find out more.**

ALS Association Statement on VA Report on Mishandled Claims from Veterans with ALS

The ALS Association is deeply concerned that the Department of Veterans Affairs (VA) has mishandled claims and deprived some veterans with ALS of the critical financial support they need, as reported in a VA Office of Inspector General Report released on November 20, 2018. Any delay in benefits for people with ALS is unacceptable. **Continue Reading.**

Upcoming Care Services Programs

December 13 **Caregiver Support Group - Eagan** December 19 **Caregiver Support Group**

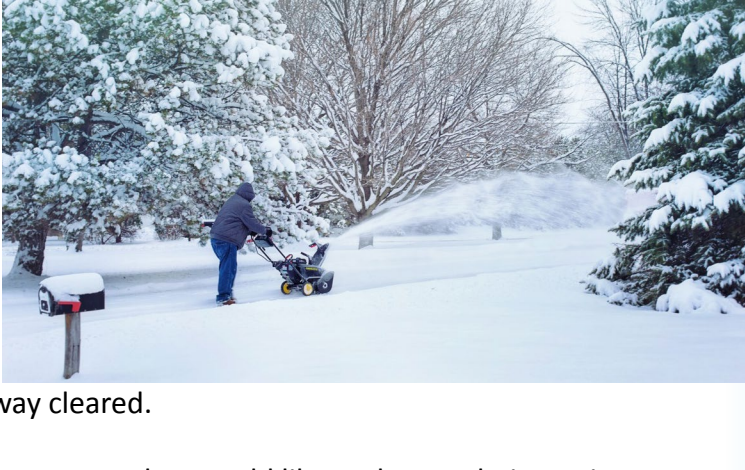
December 18 **St. Cloud Area Support Group**
Midweek Meditation - Wednesdays at 11:00 AM (CST)

hey volunteers

Snow Removal Help Needed in Orono, Fridley, and Two Harbors, MN

It's clear that winter has arrived and with it comes the need for volunteers to help people affected by ALS with snow removal. Not only are people with ALS unable to shovel or snow blow as they have in the past, a clear sidewalk and driveway is of the utmost importance because of their mobility issues.

We have three families who are currently looking for help: a family with small children in Orono who wants their driveway, sidewalk, and deck cleared; an older couple in Fridley who want their driveway cleared; and a couple in Two Harbors who also want their driveway cleared.



If you want to volunteer or if you know a snow removal company that would like to donate their services, we want to hear from you. The regular screening process will be waived for any company that is donating services.

Assist at Our Medical Equipment Loan Pool in Brooklyn Park, MN



We are looking for someone to help at our durable medical equipment (DME) loan pool housed at Reliable Medical Supply in Brooklyn Park. The ideal person will be mechanically minded, physically able to lift up to 50 pounds and walk up and down stairs, and available every Friday or every other Friday from 9:00 am – 1:00 pm.

Our DME loan pool is our most utilized program; this additional help will ensure people who request equipment receive it promptly allowing them to remain independent and safe. If this is of interest to you, view the full position description online and then fill out the **volunteer application**, selecting 'other' in the volunteer opportunities section.

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

Through the family assistance program, trained volunteers are paired with families affected by ALS to help with everyday tasks. With volunteer assistance, families report decreased stress and increased quality time together.

If you have some time to give and want to establish a relationship with someone with ALS, please consider joining this program. A list of our current requests, including location, frequency, and type of help requested, can be found on the **volunteer page** of our website.



For more information or to express an interest in these opportunities, please contact Laura Winterstein, volunteer engagement manager, at 888-672-0484 or volunteercoordinator@alsmn.org.

event news



The Development Team has grown and changed in the past few years. We know you've worked with many on the team individually, but wanted to introduce you to the full group dedicated to raising funds for the Chapter.

From Left to Right
Ryan Stauff - Vice President of Development
Stacey Donovan - South Dakota Community Outreach Manager
Hannah Yokiel - Development Coordinator (Light the Journey Gala, Strike Out ALS, Black Woods Blizzard Tour and Kolar Toyota Fishing Tournament Support)
Ashley Yoder - Development Manager (Minnesota Walks, SuperHero Dash)
Rachael Pishtek - North Dakota Community Outreach Manager
Sandy Judge - Development Manager (Black Woods Blizzard Tour, Kolar Toyota Fishing Tournament)
Gary Shipp - Development Manager (Sponsorships, Corporate and Foundation Grants, Community Fundraisers)

research updates

Mitsubishi Tanabe Pharma America to Present Data Showing Oral Version of Edaravone Processed Similarly to IV Version in Patients



Mitsubishi Tanabe Pharma America (MTPA) will present initial data on efforts to create an oral version of edaravone, a key drug in the treatment of ALS that is currently only available intravenously, during the International Symposium on ALS/MND in Glasgow, Scotland. The Symposium will be held Dec. 7-9. MTPA is expected to present results that demonstrate that oral edaravone is processed in the body in the same manner as the infused formulation. **Learn More.**



Potential New Therapy Silences SOD1 Gene in Non-Human Primates

In a promising new study by Drs. Robert Brown and Christian Mueller at the University of Massachusetts Medical School report that a type of viral gene therapy using synthetic microRNAs (miRNAs) targeting the ALS SOD1 gene is safe and effective in nonhuman primate macaques (monkeys). The ALS Association provided \$1.7 million in funding for this study, which demonstrated an efficient reduction of the SOD1 protein without side effects. This paves the way forward for further development of this potential therapy. **Continue Reading.**

ALS Organizations Collaborate to Advance New Therapeutic into Trials



Several ALS organizations announced recently that the first participant was successfully given a dose of AT-1501 in the first in-human trial of the potential treatment for ALS. AT-1501 was developed by the ALS Therapy Development Institute (ALSTDI), with support from The ALS Association, ALS ONE, and ALS Finding a Cure®, and is being brought into trials by Anelixis Therapeutics, Inc., a for-profit subsidiary of ALSTDI. **Find out more.**