

Reasons for Hope in ALS Research with the Discovery of NU-9

In a study funded in part by The ALS Association's TREAT ALS program, researchers from Northwestern University have identified the first compound (NU-9) that eliminates the ongoing degeneration of diseased upper motor neurons, a key contributor to ALS. While this news is exciting, this study has only tested the compound in mice and in laboratory neurons and is in the very early stages.

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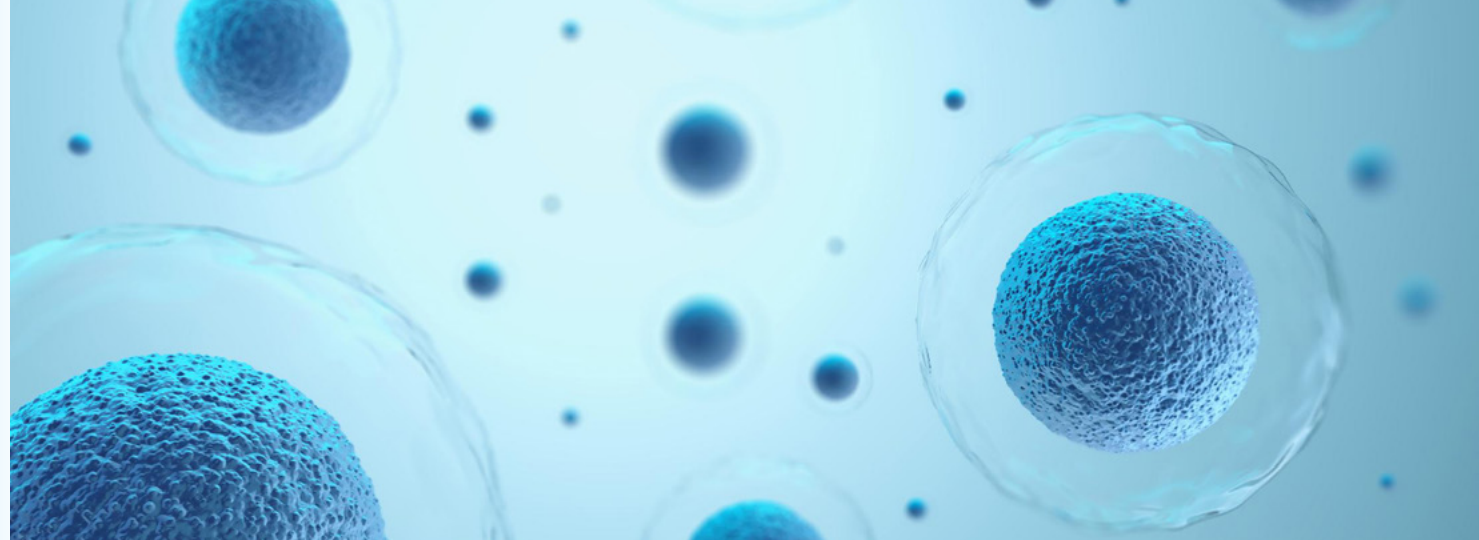
Preparing for a Medical Emergency While Living with ALS



People living with ALS will likely experience complications related to the disease that warrant a visit to the hospital at some point in their journey. At the same time, they are not immune from other injuries or medical issues—people with ALS can still get sick or possibly hurt themselves in ways unrelated to the disease. Making the conscious choice to be prepared can make all the difference.

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Infusion of Funding Speaks to Promise of Treg Therapy Research



There have been studies that have shown that in people living with ALS, Tregs are reduced and the lower the Tregs, the faster the progression of ALS. In this article, Dr. Kuldeep Dave, vice president of research at The ALS Association, discusses the science of Tregs.

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April is National Occupational Therapy Month!

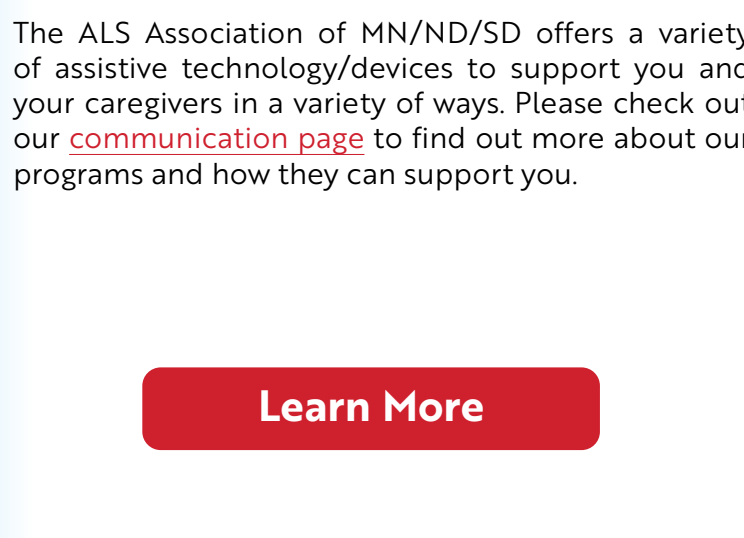
Occupational therapy focuses on helping people do the things they want and need to do throughout the day. This includes anything that “occupies” your day, such as dressing, eating, bathing, etc. The goal of occupational therapy is to maintain an individual’s independence for as long as possible and improve their quality of life.

Occupational therapists (OT’s) are an important part of your care team and can be seen at your ALS clinic, or other facility that has been ordered by your doctor. Some of the things they may be able to assist with are listed here:

1. Activities of Daily Living (ADL’s)—your occupation therapist will recommend DME/Adaptive Equipment to increase safety/independence with daily activities, as well as train you how to use these items. There are also some helpful self-care tips on page 17 of our ALS Navigation Tool.
2. Caregiver Education—they will train your caregivers to assist with ADL’s, use DME and adaptive equipment, safe transfer techniques to prevent injury, and positioning.
3. Energy conservation-fatigue is a common symptom of people with ALS. Page 19 of our ALS Navigation Tool provides you with ideas on how to focus your energy on things that are most important to you.
4. Home Safety—your occupational therapist will recommend home modifications to increase safety and efficiency in your home. We have our Smart Home products that will improve independence with environmental controls, conserve energy, call for help, and prevent falls. Page 18 of our ALS Navigation Tool will provide you with some helpful hints on staying safe in your home.
5. Exercise—your OT can provide you with some gentle exercises to increase strength and flexibility in your working muscles, as well as provide splinting recommendations for joint stability to increase a joint function or prevent deformity.

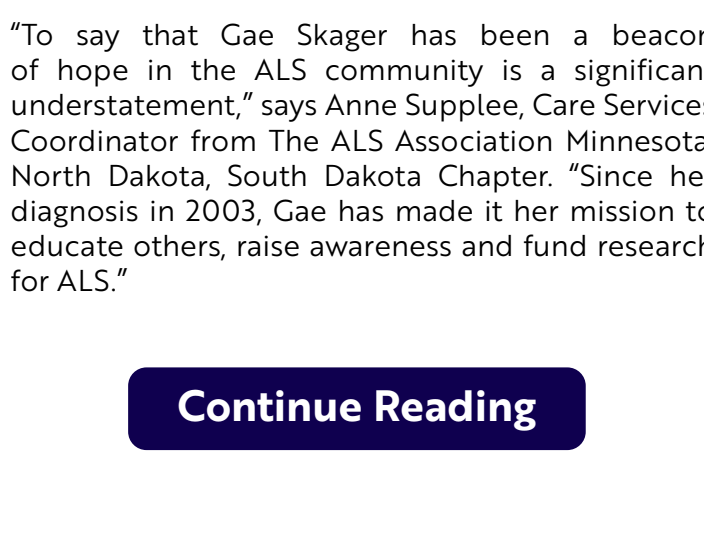
If you are fortunate enough to have an OT in your life, thank them. If you do not have an OT, reach out to your doctor to see if they can connect you with one, I think you will be happy you asked.

April 14th is Assistive Technology Awareness Day!



The ALS Association of MN/ND/SD offers a variety of assistive technology/devices to support you and your caregivers in a variety of ways. Please check out our [communication page](#) to find out more about our programs and how they can support you.

Geraldine Skager: A True Hero



“To say that Gae Skager has been a beacon of hope in the ALS community is a significant understatement,” says Anne Supplee, Care Services Coordinator from The ALS Association Minnesota, North Dakota, South Dakota Chapter. “Since her diagnosis in 2003, Gae has made it her mission to educate others, raise awareness and fund research for ALS.”

[Learn More](#)

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ALS Advocacy Efforts

Thanks to everyone who participated in our Advocacy Fly-In event. This event, held every year in March, gives us an opportunity to talk with our Members of Congress and share topics that are important to the ALS community. This year we focused our efforts on seeking funding for ALS research. [These are big asks, but ones that are critical for our continued work to find treatments for ALS.](#)

If you have questions about our advocacy work, please reach out to Marianne Keuhn, Vice President of Care Services at marianne@alsmn.org or 612-455-8334. Below you will find more information on our appropriations (budget) asks:

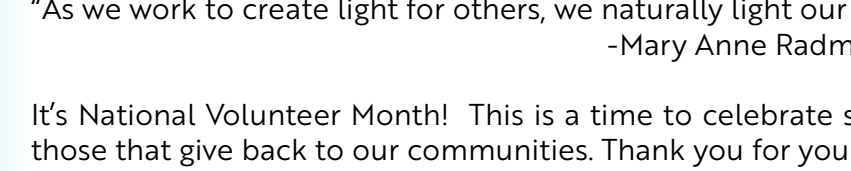


- Increase funding to at least \$130 million for ALS research at NIH to accelerate discovery and development of new treatments and increase the number of ALS clinical trials.
- Increase funding to at least \$60 million for the DOD ALS Research Program (ALSRP) to fund clinical trials to pull through promising preclinical research and human studies into ALS drug development.
- Provide at least \$50 million for the Orphan Products Grants Program at FDA specifically to fund ALS research to expedite product development, foster innovative trial designs, and increase the number of ALS clinical trials to better understand the disease progression and pathology.
- Provide at least \$10 million for the CDC National ALS Registry and Biorepository to help researchers identify candidates for clinical trials, identify risk factors for ALS and collect biological samples that will aid the search for treatments and a cure.

Upcoming Care Services Programs

April 7	Minneapolis/St. Paul Metro Area Support Group (Virtual Meeting)	April 20	Young Adult Hangout (Virtual Meeting)
April 8	Northern MN Support Group (Virtual Meeting)	April 21	Family Caregiver Support Group (Virtual Meeting)
April 8	Family Caregiver Support Group (Virtual Meeting)	April 27	SD and Southern MN Support Group (Virtual Meeting)
April 20	ND and Central MN Support Group (Virtual Meeting)		

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



National Volunteer Week is April 18-24!

“As we work to create light for others, we naturally light our own way.”
—Mary Anne Radmacher

It's National Volunteer Month! This is a time to celebrate service and those that give back to our communities. Thank you for your service to the ALS community and for being a part of our team.

Although the utilization of our incredible network of dedicated volunteers had to be adjusted this past year, we remain grateful for all that you have done to help move our mission forward through the giving of your time. Whether you've helped with an event that raised awareness and funds, provided administrative support in the office, or worked directly with one of our programs, your efforts make a positive difference. Last year, we served 608 people navigating the challenges of ALS throughout our three state region. Your time and energy makes the support we provide these individuals and their families possible. We couldn't do it without you.

If you have any questions about volunteering, the volunteer positions available, or the application process, please call 888-672-0484 or email volunteer@alsmn.org.



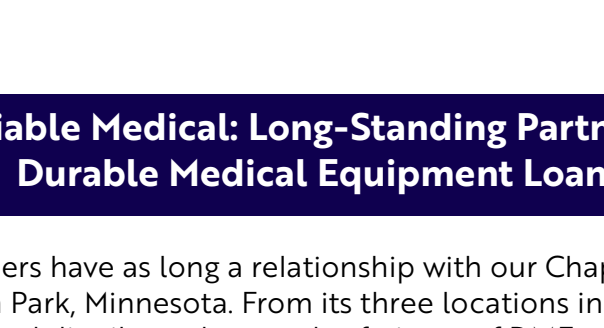
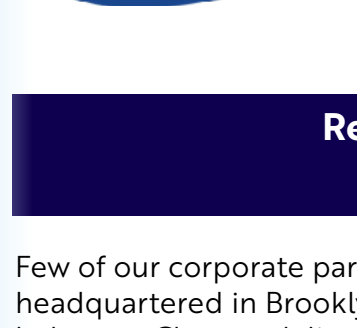
Sing Golf - Teams, Sponsors, & Auction Items

Preparations for the Larry Sing Memorial ALS Golf Classic are underway for the 27th year! We are seeking out participation and support at all different levels, from sponsors to golfers and donations to our auction. This annual event, held in Fargo and Moorhead, raises funds for The ALS Association's mission, including the Hrbek-Sing Communication and Assistive Device Program, which provides individuals with ALS critical technology that helps them continue to communicate when ALS has compromised their ability to speak.

In 2020, the hardworking volunteer committee was able to pull off the event at Moorhead Country Club, raising over \$50,000 while upholding COVID precautions, and we hope to double our impact in 2021. Introducing new on-course activities and utilizing an online auction platform are some of the new changes that will remain in 2021.

Until May 1st, receive \$50 off of the registration for a team of four golfers with the code “TEAM50” when registering on the website: [found here](#).

Thank you to our Gold Level Sponsors - if you are interested in [becoming a sponsor](#), or have any questions about this event, please contact Rachael Pishtek at 612-672-0484 or rachael@alsmn.org or Ryan Stauff at 612-455-7238 or ryan@alsmn.org.

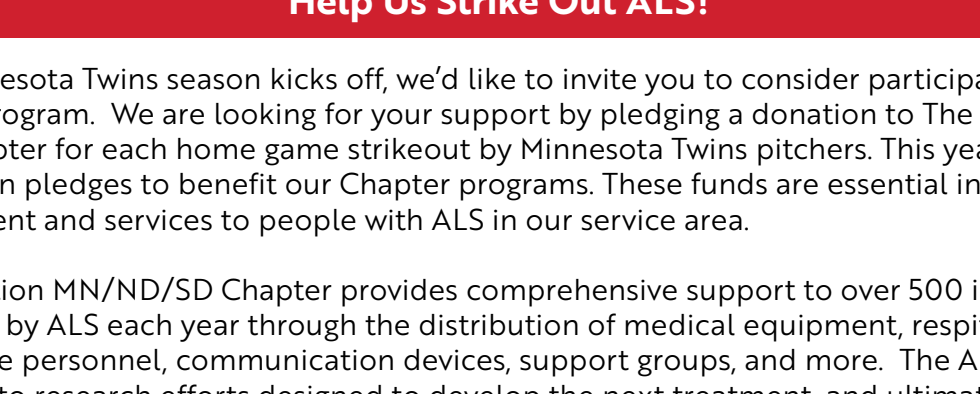


Reliable Medical: Long-Standing Partner for our Durable Medical Equipment Loan Pool

Few of our corporate partners have as long a relationship with our Chapter as [Reliable Medical](#), headquartered in Brooklyn Park, Minnesota. 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 also houses the Chapter's largest DME loan, with over 900 pieces on-site at any given time.

Reliable Medical continues to be a supporter of our Chapter's events, and this year marks the 15th year of sponsorship of the Minnesota Walk to Defeat ALS. Beyond this year's Momentum sponsorship of \$5,000, Reliable Medical will continue its tradition of fundraising in support of our Chapter through its Walk Teams in Rochester, St. Cloud, and the Twin Cities. To date, Reliable's Walk Teams have raised \$22,000 and counting through creative fundraisers and advocacy of our work. Thank you, Reliable Medical, for your continued support of our community and impact on our work! Learn more about this year's support by checking out their website: <https://www.reliamed.com/mn-als-walk>

Interested in [joining us](#) as a sponsor? Please reach out to Gary Shipp, gary@alsmn.org or 612-455-8325 to learn more.



Help Us Strike Out ALS!

As the 2021 Minnesota Twins season kicks off, we'd like to invite you to consider participating in the 2021 Strike Out ALS Program. We are looking for your support by pledging a donation to The ALS Association, MN/ND/SD Chapter for each home game strikeout by Minnesota Twins pitchers. This year, we are hoping to raise \$12,500 in pledges to benefit our Chapter programs. These funds are essential in providing much needed equipment and services to people with ALS in our service area.

The ALS Association MN/ND/SD Chapter provides comprehensive support to over 500 individuals and families affected by ALS each year through the distribution of medical equipment, respite care from skilled home care personnel, communication devices, support groups, and more. The ALS Association also contributes to research efforts designed to develop the next treatment, and ultimately, a cure for the disease. As we move through 2021, our Chapter remains focused on meeting the evolving needs of the ALS community in the safest way possible, while continuing to fight for a world without ALS. Your generosity can make an impact in a time it is very much needed.

If you are interested in making a pledge, please follow the [link to our pledge form](#). If you have any questions or would like to make a one-time donation to the program, please contact Rachael Pishtek at 612-672-0484 or rachael@alsmn.org.

