



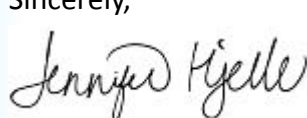
Celebrating 25 Years of Service

In 1993, The Minnesota Chapter of The ALS Association opened its doors with the intent of providing compassionate care and support to individuals and families living with ALS. Today, 25 years later, we maintain the same core values across three states as we seek to innovate in the areas of ALS advocacy, research, and care services.

As you **take a look at the timeline of milestones** we've prepared to summarize 25 years of service in our region, you'll see how much we've grown. But our hope is that you'll also recognize that none of this work would have been possible without the generosity and support of our community. You have been by our side for the last two and a half decades, and for that reason we are hopeful about a future that looks very different from today. A future with multiple treatments and advanced support options.

On behalf of our Board of Directors, staff, and the families we serve in Minnesota, North Dakota and South Dakota, thank you for helping build a future without ALS.

Sincerely,



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

care corner

Invasive Ventilation: A Difficult But Necessary Conversation

Accepting invasive ventilation is a huge endeavor that can prolong life. However, it may not be recommended for many individuals based on their personal values, wishes and needs. This article written by Dr. Sam Maiser, Neurologist, Palliative Care Physician, and Medical Director of the ALS Center of Excellence at HCMC and Lisa Kronk, RN, Care Services Coordinator at The ALS Association, MN/ND/SD Chapter provides practical and honest information needed to make a life changing decision. [Click here](#) to read more.



INVASIVE VENTILATIONa difficult but necessary conversation.

Dr. Sam Maiser, Neurologist, Palliative Care Physician, & Medical Director of the ALS Center of Excellence at HCMC and Lisa Kronk, RN, The ALS Association, Minnesota, North Dakota, South Dakota Chapter

In people with ALS, the muscles that support the lungs and assist with breathing will weaken just as muscles in the arms and legs, or those involved in speaking, do. As the breathing muscles weaken, a physician will evaluate the individual for the use of a **noninvasive** ventilator. This ventilator, often referred to as an AVAP or Bi-Pap for short, is used with a mask worn over the nose, or nose and mouth, and is typically used when someone is lying down (for naps and/or for sleep). The noninvasive ventilator may help eliminate feelings of shortness of breath, improve sleep and/or reduce morning headaches, improve daytime fatigue, all of which may be caused by a buildup of carbon dioxide (a gas formed by breathing) in the body due to the weakening breathing muscles. For some, the transition to using a device like this goes very smoothly while for others, especially those with bulbar symptoms (speaking and swallowing difficulties), it may be something they are never able to tolerate. Also, some individuals with ALS who have hand weakness may not feel comfortable using the device because they cannot independently put on or take off the mask.

For those who use noninvasive ventilation successfully, there will come a point when the breathing muscle weakness is so severe they can no longer blow out the carbon dioxide that builds up in their blood stream, even with a noninvasive ventilator. When that happens, a person with ALS will have two choices. One, they can be enrolled in hospice and receive care that will keep them comfortable and that



Online Support Group Meetup: Rochester

For anyone near Rochester interested in gathering to participate in our **Online Support Group**, we will meet

When: 1st Tuesday of each month from 3-4 pm CST

Where: Rochester Community and Technical College

Heintz Center Room 113
1926 Collevue Rd SE
Rochester, MN 55904

hey volunteers

Celebrate Success by Volunteering at the Black Woods Blizzard Tour in Duluth



In its 19th year, the Black Woods Blizzard Tour is the largest fundraising snowmobile tour in the world. Last year participants raised more than \$1 million and this year we're hoping to maintain that momentum to support families in our region.

We are looking for volunteers to help with our silent auction and with selling raffle tickets, ALS branded merchandise, and mystery bottles of wine. Various shifts are available from 3:30 pm - 11:00 pm on Saturday, February 10.

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 manager, at 888-672-0484 or volunteercoordinator@alsmn.org.



event news



Join us for the 2018 Black Woods Blizzard Tour!

The single largest snowmobile fundraiser in the world is about to happen, and you can help us reach our \$1 million goal! There's still a few spots left, don't wait, **secure your spot today!** Not a snowmobiler? Show your support for the Black Woods Blizzard Tour another way, **donate an item to the silent auction**, join us at the **Celebration Dinner**, or **make a donation** to a rider or the event. **Contact Sandy** or check out **our website** for all the details!

Join the Movement!

Spring and Summer Walk registration is now open! Our newly redesigned website is up and running, and ready to take your registration. You'll enjoy all of our tools that are proven to help you raise more money, all with a fresh look! Your participant center will be your landing page for fundraising success, guiding you through the steps to ensure you're headed in the right direction.

Don't forget to mark your calendars for our Spring/Summer Walk Dates!

Mankato - May 6
Bismarck - June 16
Rapid City - June 23

Ready to get started and help us defeat ALS? Contact your Walk Coordinator today to register and learn how you can be part of the quest for a cure. Mankato Walk - Ashley Yoder (ashley@alsmn.org or 612-455-8330), Bismarck & Rapid City Walks - Chelsea Cronin (chelsea@alsmn.org or 605-274-0230).



research updates

Neruo Collaborative Researcher

Dr. Finkbeiner Partners with Eli Lilly and Company

Dr. Steven Finkbeiner of the Gladstone Institutes recently announced a research partnership with Eli Lilly and Company to move his ALS research forward. Dr. Finkbeiner is a member of California-based Neuro Collaborative, an ALS Association-funded initiative focused on discovering new ALS therapeutics and moving them into clinical trials. This multi-year, milestone-driven project is using innovative robotic microscope technology to focus on better understanding neurodegenerative diseases, with a large focus on ALS. [Continue reading.](#)



Training Program Gives Young Caregivers Confidence, Peer Support



Youth who help care for their loved ones with ALS are learning about important areas of ALS care from physical therapy, occupational therapy, and speech therapy, to social work and neurology — through YCare, an education and support program developed and directed by Dr. Melinda S. Kavanaugh, Assistant Professor of Social Work with the Helen Bader School of Social Welfare at the University of Wisconsin-Milwaukee. [Find out more.](#)