



## Celebrating 20 Years of the Black Woods Blizzard Tour



For two decades, The Black Woods Blizzard Tour has been raising funding and awareness for ALS. This year, during the event's 20th Anniversary, a record \$1,229,000 dollars was raised in support of research and services provided by The ALS Association, MN/ND/SD Chapter. The three day snowmobile ride concluded with a banquet held at Cirrus Aircraft in Duluth on Saturday, February 2nd. Twins legends Kent Hrbek, Ron Gardenhire, Terry Steinbach, and Jack Morris were joined by Tigers great, Kirk Gibson, as they celebrated with a crowd of more than 700. This makes three consecutive years that the event has crossed the million dollar mark, bringing its lifetime total over \$10 million.

"Year after year this group of extraordinary people manages to inspire us with their generosity," said Chapter Executive Director, Jennifer Hjelle. "We knew they'd want to go big for the 20th year, but the fact that they raised the bar once again is incredible and it will go such a long way to help the 600 families facing ALS that we serve."

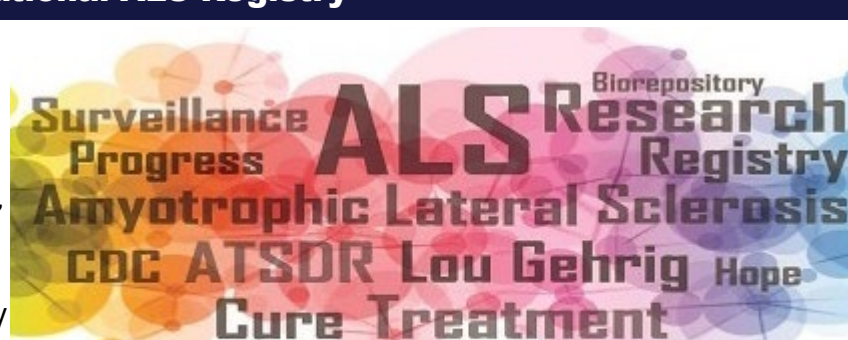
"The people who ride, volunteer, sponsor and support this event are amazing," added Hjelle. "Their efforts continue to offer hope for everyone who has been impacted by this disease and it motivates our staff to keep moving forward until we live in a world without ALS."



## National ALS Registry

Do you know about the National ALS Registry? If you are a person with ALS or have a loved one with ALS, you should.

The National ALS Registry, launched in 2010, is a congressionally mandated registry for persons living with ALS in the United States (U.S). It is the only population-based registry in the U.S. that collects information to help scientists learn more about who gets ALS and its causes.



The registry will collect vital risk factor information about ALS that may help identify the cause or causes of ALS. If you have the disease, consider joining the registry and completing the risk-factor surveys because the information provided can make a difference in the fight against ALS. If you have a loved one with ALS, please encourage them to enroll and/or assist them if they need help enrolling (e.g., no computer/email). The information provided is stored and protected by the Agency for Toxic Substances and Disease Registry, and a person's name is never shared; their privacy is protected.

When someone enrolls in the National ALS Registry, participants will have an option to receive ALS research updates via email and an option to participate in the National ALS Biorepository. A biorepository is the collection and storage of samples of biological material. These samples could include blood, urine, tissue, cells, DNA, and proteins. Samples may be used for future research. To learn more about the biorepository, [click here](#).

To enroll in the registry, the secure web portal is: <https://www.cdc.gov/als> or [click here](#). Once you have created an account, just remember the username or password you used to create it and then you can go back in at your leisure to take the 17-18 surveys on the site. The surveys will collect demographic information, occupational history, physical history, exposure to chemicals, and much more. There is even a survey where you can share what you think caused your ALS or ALS in general.

If you have questions about the registry or the process, please feel free to contact Lisa Kronk, RN, at the Chapter office ([lisa@alsmn.org](mailto:lisa@alsmn.org) or 888.672.0484).

## Waive the Five-Month SSDI Waiting Period

We have great news of critical importance to Americans confronting ALS.

January 31 marked the beginning of the process to reintroduce the ALS Disability Insurance Access Act. This bill would waive the five-month Social Security Disability (SSDI) waiting period before people with ALS receive access to SSDI benefits. In the Senate, Sheldon Whitehouse (D-RI) and Tom Cotton (R-AR) began circulating a letter requesting original sponsors, while Reps. Seth Moulton (D-MA) and Peter King (R-NY) did the same in the House. [Click here](#) to find out more.



## Upcoming Care Services Programs

February 19	<b>St. Cloud Area Support Group</b>	February 20	<b>Family Caregiver Support Group</b>
February 19	<b>Young Adult Hangout</b>	February 26	<b>Mankato Area Support Group</b>
Midweek Meditation - Wednesdays at 11:00 AM (CST)			



## Mark Your Calendar - Special Event Dates Finalized

The dates for our 2019 **special events** have been set. The money raised from these events fund ALS research and the programs and equipment we provide free of charge to people affected by ALS. Volunteers are integral to the success of these events so mark your calendar if you'd like to volunteer.

We need Saturday morning volunteers for the Walk to Defeat ALS events and the **SuperHero 5K/10K Dash** in St. Paul, MN on Saturday, May 11.



### Walk to Defeat ALS

MN: Mankato | April 27  
MN: Rochester | August 24  
MN: St. Cloud | September 7  
MN: St. Paul | September 14

ND: Bismarck | May 18  
ND: Fargo | August 10

SD: Rapid City | June 15  
SD: Sioux Falls | September 21

We are looking for daytime and evening volunteers for the **Larry Sing Memorial ALS Golf Classic** in Fargo/Moorhead on Monday, August 26.

We need volunteers to help plan the **Light the Journey Gala** and to set up and help at the event in Bloomington, MN on Saturday, October 26.

After marking your calendar, you can let Laura at 888-672-0484 or [volunteercoordinator@alsmn.org](mailto:volunteercoordinator@alsmn.org) know of your interest in volunteering.

## 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](mailto:volunteercoordinator@alsmn.org).






## SuperHeroes Assemble!

While running outside isn't always the first thing that comes to mind when temperatures are below zero, eventually the weather will get nicer, so mark your calendars for the **2019 ALS SuperHero 5k/10k Dash**. This year's event will be held on Saturday, May 11, at Raspberry Island in St. Paul and promises to be a fun and meaningful experience. Last year's Dash was the largest in the event's history with more than 925 superheroes and over \$176,000 raised. We hope you can help us build on that momentum for another successful event in 2019. Pull your band of heroes together, form a team, and join us as we make a positive difference for individuals living with ALS and their families. For more information or to register your team, [click here](#).



## Upcoming Special Events

 April 27	<b>Mankato Walk</b>	 May 11	<b>ALS SuperHero Dash</b>	 May 18	<b>Bismarck Walk</b>
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## The ALS Association and The Tow Foundation Commit Additional \$6 Million to New York Genome Center

The ALS Association and The Tow Foundation are pleased to announce their continuing support of the New York Genome Center's (NYGC) Center for Genomics of Neurodegenerative Disease (CGND), in recognition of the substantial genomic research being carried out by NYGC scientists. The ALS Association has committed an additional \$3.5 million to the NYGC's CGND, including a \$1 million commitment from the Association's Greater New York Chapter. The Tow Foundation in New Canaan, CT, has contributed an additional \$2.5 million gift. [Learn more.](#)



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