

Never Surrender Inc. Invests Over

\$1 Million to Support the

ALS Community



ALS news and

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In 2019, an ambitious group of caring individuals whose goal is to provide support to those living with ALS formed Never Surrender Inc, a new nonprofit organization established to lead and manage the amazing work of the Kolar Toyota ALS Fishing Tournament and the Black Woods Blizzard Tour. The Kolar Toyota ALS Fishing Tournament is a 25 year tradition that has raised more than \$3.5 million while becoming one of the largest fishing competitions in Minnesota. Over the course of 21 years, the Black Woods Blizzard Tour has raised more than \$12.4 million and become the world's largest snowmobile fundraising event. Collectively, Never Surrender has taken these events to new heights with record participation and over \$1.3 million raised in 2020 alone. In addition to raising critical funding and awareness, the Black Woods Blizzard Tour and the Kolar Toyota ALS Fishing Tournament have built an incredible community of riders, anglers, volunteers and sponsors unified in their unwavering commitment to making meaningful progress towards finding a cure for the disease.

With an overwhelming response to the Black Woods Blizzard Tour and the Kolar Toyota ALS Fishing Tournament last year, Never Surrender focused on how the dollars raised from these events could make a difference. Through extensive work understanding the ALS landscape and the greatest needs of those navigating the disease, Never Surrender turned to The ALS Association. As a result, Never Surrender invested over \$1 million in specific programs and services of the Chapter in 2020, including the Durable Medical Equipment Loan Pool, Hrbek-Sing Communication and Assistive Device Program, Jack Norton Family Respite Program, Family Assistance Program, support groups and ALS Certified and Recognized Centers of Excellence. The collective contribution to these programs and services comprises the single largest annual investment in The ALS Association MN/ND/SD Chapter's history.

"The incredible generosity of Never Surrender Inc. and the community of supporters that surround it is making a monumental difference for those we serve in a year when it is very much needed." said Phil Albert, ALS Association Board Chair. "As individuals and families face greater challenges as a result of the pandemic, Never Surrender has ensured the Chapter can meet these challenges head on while continuing to maintain the highest quality of care and our organization, along with the entire ALS community, is grateful."

While 2020 has created unprecedented needs, investments like this demonstrate that the response to those needs can also be unprecedented. Thank you, Never Surrender, for your tremendous commitment to individuals and families in the fight against ALS.



Never Surrender Inc. Funding the Fight Against ALS



Care corner



The ALS Disability Insurance Access Act went into law on December 22, removing the 5-month delay for

people with ALS to access the Social Security Disability benefits. This marks the culmination of a multi-year fight by ALS advocates across the country. The law will not go into effect immediately because the Social Security Administration must write rules for how it will be implemented, typically taking around 60 days following signing of a bill.

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ALS Association Working With State, Federal Officials to Make Sure ALS Community Can Access COVID-19 Vaccines



As the approval, production and distribution of COVID-19 vaccines unfolds, The ALS Association will continue to work with the CDC and states to make sure people with ALS and their caregivers can access vaccines as they become available.

Updated information and resources will be available at <u>The ALS Association's COVID-19 Vaccine Information</u> hub.

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What We Know About Second COVID-19 Vaccine to Get FDA Approval



The FDA approved emergency authorization of a COVID-19 vaccine developed by Moderna, the second vaccine approved by the agency to combat the coronavirus pandemic. Like the Pfizer vaccine, the Moderna vaccine is administered in the muscle as a series of two doses. Unlike the Pfizer vaccine, the Moderna vaccine can be stored at normal freezer temperatures, and should be easier to distribute.



Support Group Changes for 2021

We have made some changes to support group for 2021. There is a new monthly education hour for those that want information about ALS, symptom management and resources. We have also made changes to each of the support groups. Learn more below or on our <u>website</u>.



Presentations about topics of interest to those living with ALS and their families.

Each presentation will be recorded and posted for later viewing.

First Tuesday, 3:00-4:00 p.m. Central Time For information and links to join, contact anne@alsmn.org or call 888-672-0484 , ext. 1050.

Minneapolis/St. Paul Metro Area

First Wednesday, 12:00-1:15 p.m. For more information and links to join, contact anne@alsmn.org or call 612-672-0484

Northern MN

Second Thursday, 10:30-11:30 a.m. For more information and links to join, contact anne@alsmn.org or call 612-672-0484

North Dakota and Central MN

Third Tuesday, 12:00-1:30 p.m. For more information and links to join, contact jennifer@alsmn.org or call 612-672-0484

South Dakota and Southern MN

Last Tuesday, 3:30-4:30 p.m. For more information and links to join, contact jennifer@alsmn.org or call 612-672-0484

Sponsored by The ALS Association, MN/ND/SD Chapter

2nd Thursday Family Caregiver Support Group Second Thursday, 6:30-7:30 p.m. For more information and links to join, contact jennifer@alsmn.org or call 612-672-0484

3rd Wednesday Family Caregiver Support Group Third Wednesday, 7:00-8:00 p.m.

For more information and links to join, contact jennifer@alsmn.org or call 612-672-0484

Young Adult Hangout Support Group This group is for young adults (18+) that have a parent with ALS. Third Tuesday, 7:00-8:00 p.m. For more information and links to join, contact anne@alsmn.org.

Upcoming Care Services Programs

January 14	Northern MN Support Group (Virtual Meeting)	January 20
January 14	Family Caregiver Support Group (Virtual Meeting)	January 26
January 19	ND and Central MN Support Group (Virtual Meeting)	February 3
January 19	Young Adult Hangout (Virtual Meeting)	

Family Caregiver Support Group (Virtual Meeting) SD and Southern MN Support Group (Virtual Meeting) Minneapolis/St. Paul Metro Area

Support Group (Virtual Meeting)

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



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. However, because of the ongoing COVID-19 pandemic, volunteers are currently only assisting with outdoor tasks.

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.







Despite the many challenges caused by COVID-19 this past year, ALS research made strides toward finding effective treatments for ALS. As 2020 winds down, we wanted to share an update from our partners at Biogen on some of their ongoing research projects.

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Unite in the Fight Against ALS at the 2021 Black Woods Blizzard Tour!

You can support the 2021 Black Woods Blizzard Tour by bidding on fantastic items in the event's silent auction, which will be going live on January 15th. Anyone can sign up to bid and win prizes by accessing the following link: <u>https://neversurrender.cbo.io</u>.

You can also be a part of this world class event by tuning into the 2021 Black Woods Blizzard Tour Virtual Program/Banquet on Saturday, February 6th. Follow https://www.facebook.com/blackwoodsblizzardtour to watch and participate in the program or visit www.BlackWoodsBlizzardTour.com, which contains the Facebook link, direct livestream program link and more.

Meet the Dev Team



Ryan Stauff

Office from: St. Paul, MN Favorite Part of 2020: Seeing constituents engage with our events and my kids yelling in the background of a National call.

Office from: St. Paul, MN Corporate Sponsors, Grant Foundations, Individual Donors, MN Events Favorite Part of 2020: Completing my master's degree



Gary Shipp



Office from: Hudson, WI Twin Cities Metro Events Favorite Part of 2020: Time spent with our 7-month old daughter, Hazel

Ashley Yoder

Office from: Harrisburg, SD Walk to Defeat ALS, Special Event Volunteer Coordination, Community Fundraisers Favorite Part of 2020: Watching my daughter perform in Show Choir before school was changed to online learning.



Stacey Donovan



Rachael Pishtek

Office from: Fargo, ND

Walk to Defeat ALS, Strike Out ALS, The Larry Sing Memorial ALS Golf Classic, Giving Hearts Day Favorite Part of 2020: Rediscovering my love for reading works of fiction!

Office from: Minneapolis, MN Walk to Defeat ALS, Community Fundraisers Favorite Part of 2020: I enjoyed a trip to Australia right before everything shut down due to the pandemic last spring!

G connect with us



Hannah Bremer

