



## HOPE DRIVES LIFE

At Never Surrender Inc., we have one goal, and that is to help people live with ALS. Our organization was built when one of our family members, Kevin Kolquist, was diagnosed with ALS. Kevin always said, "hope drives life", and that is what we aim to do at Never Surrender.

We offer three VIP experiences where our fundraising participants combine their passion for fighting ALS with a passion for the great outdoors: Black Woods Blizzard Tour, Kolar Toyota ALS Fishing Tournament, and Tomassoni Tour - Cycle for ALS.

We will continue to push fundraising limits in hopes of ending this disease. We will *Never Surrender to ALS*.

**MAKE A DIFFERENCE.  
HAVE FUN.  
REGISTER TODAY.**



Black Woods Blizzard Tour  
February 11-14, 2026



Kolar Toyota ALS Fishing Tournament  
May 30 & 31, 2025



Tomassoni Tour  
September 18-20, 2025

# *Never Surrender Inc.*

*Funding the Fight Against ALS*

## **YOU Are NSI : 2024 Funding**

**Never Surrender Inc made over \$2 million worth of difference in the Fight Against ALS in 2024!**

We want to express our heartfelt gratitude to our participants, volunteers, and sponsors for supporting people living with ALS and their families. Your contributions were used to make an immediate impact in the daily lives of those battling this challenging disease AND to expand research that will help find a cure. Here's how the funds were put to work in 2024:

### **1. Direct Patient Support and Equipment Access**

Your contributions funded resources that provide people living with ALS greater independence and quality of life. Thanks to your work, Never Surrender Inc provided funding to:

- **ALS Association: Durable Medical Equipment Loan Pool** to provide equipment such as power wheelchairs, adaptive utensils, and more to help people living with ALS and their caregivers
- **ALS Association: Communication Devices**, providing the Hrbek-Sing Communication & Assistive Devices, smart home technology, and eye-gaze devices so that individuals living with ALS can maintain their independence
- **Miller Dwan Foundation's Northland Adaptive Recreation** to provide recreational equipment, including adaptive bikes and fishing rods to people living with ALS

### **2. Research Advancements**

Your donations also helped fund research projects in our region that are aimed at finding treatments and ultimately a cure for ALS. Your generosity expanded access to clinical trials and fueled groundbreaking studies, providing hope that future treatments will improve patients' quality of life and slow disease progression. The research and treatments that you made possible include:

- **Massachusetts General Sean Healey ALS Platform Trials – Expanded Access Program (EAP) at Essentia Health and University of Minnesota**

The EAP program allows people in Minnesota, Northern Wisconsin, and surrounding areas who have been living with ALS who don't qualify for traditional trials due to the progression of their disease to have access to investigational medical treatment.

- **Massachusetts General Sean Healey ALS Platform Trials – Acceleration Center of Enrollment (ACE) at the University of Minnesota**

The ACE center will streamline enrollment and make operational improvements, thereby increasing access to clinical trials, expanded access protocols, and non-therapeutic research studies. This will improve the experience for study participants in ALS clinical research throughout the upper Midwest territory.

- **ALS Therapy Development Institute (TDI) – ALS Research Collaborative (ARC)**

ALS TDI is the largest research lab in the world focused entirely on ALS research. Your funds will be used to enroll 25 additional people with ALS in the Upper Midwest into TDI's ARC that provides customized information to enrollees about their disease progression and the effectiveness of their interventions while also advancing research nationwide by allowing researchers across the world to better understand the underlying biology of ALS.

- **ALS Therapy Development Institute (TDI) - Develop new induced pluripotent stem cell (iPSC) derived motor neurons**

The ability to test drugs on patient-specific motor neurons holds the promise of more personalized medicine, thereby increasing the likelihood of clinical success.

Thank you for Funding the Fight Against ALS! With your help, we will Never Surrender to ALS!

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**TOTAL AMOUNT OF FUNDING PROVIDED IN 2024: \$2,002,000**

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# News from the University of Minnesota

## ALS Center of Excellence

### Research Opportunities

#### Never Surrender Expanded Access Program

Never Surrender Inc., through Massachusetts General Hospital, has generously provided funding to the University of Minnesota to support Expanded Access Programs (EAPs) in ALS. We have completed enrollment in one EAP under this program and are moving forward with two additional expanded access programs. For more information on the current EAP opportunities, please contact Julia Munoz ([munoz156@umn.edu](mailto:munoz156@umn.edu)).

#### Multicenter ALS Imaging Study

The purpose of the study is to test new biomarkers of ALS using MRI scans. A biomarker is a measurable characteristic that can be used as an indicator of a particular disease state. Identifying biomarkers in ALS will help test new treatments and may help us make diagnoses earlier. Please visit the study website for eligibility information and to contact a research coordinator to enroll: <https://studyfinder.umn.edu/studies/31594>

#### Biorepository to Support ALS Research in Minnesota

The Minnesota ALS Biorepository at the University of Minnesota is a state-sponsored effort to provide critically needed samples of biological specimens to advance ALS research. The Biorepository collects blood and other biological specimens from people living with ALS, healthy individuals without ALS, and people with some other neurological diseases. In addition, the biorepository coordinates donation of brain and spinal cord specimens obtained after death from people who had ALS, to further ALS research. Please visit the study website for eligibility information and to contact a research coordinator to enroll: <https://studyfinder.umn.edu/studies/31786>

#### HEALEY ALS Platform Trial

The HEALEY ALS Platform Trial is a research trial that tests the safety and effectiveness of multiple treatments in ALS. A regimen is a specific course of treatment, each with a different study drug. We are doing this research to find out if different treatments have an effect on ALS. We also want to find out if these treatments are safe to take without causing too many side effects. Please visit the study website for eligibility information and to contact a research coordinator to enroll: <https://studyfinder.umn.edu/studies/22142>

#### Clinic-Based Multi-Site ALS Natural History & Biofluid Study

This is a clinic-based natural history study and registry. Once a participant enrolls in the study at the clinic all data collection will occur remotely. At this point in time, we are only able to enroll patients who are currently being served by the Natural History Consortium ALS Clinics. Biospecimen (e.g. blood) collection will be done at the UMN ALS Clinic in alignment with the participant's care schedule. More information can be found at this website: <https://alsnaturalhistory.umn.edu/>

#### **Upcoming Educational Webinars hosted by University of Minnesota**

If you are interested in attending a webinar, please email Amanda Rueter at [arueter@umn.edu](mailto:arueter@umn.edu) with your name, email address, and webinar of interest (or state that you are interested in all of them!)

*April 30th 1:00PM CDT*

*Topic: Update on ALS Research in Minnesota and Beyond*

*Presenter: Dr. David Walk, University of Minnesota*

*June 18th 12:00pm CDT*

*Topic: Rural Care for ALS Patients*

*Presenters: Dr. Susan Scarberry & Brooke Campbell, DNP, Sanford Health*

*TBD – September 2025*

*Topic: Tasty Meals at Any Texture*

*Presenter: Dr. Samuel Maiser, Hennepin Healthcare*

*November 13th – 11:00am CST*

*Topic: Stem Cells and ALS*

*Presenter: Dr. Nathan Staff, Mayo Clinic*

## 26th Annual Black Woods Blizzard Tour Raises Over \$1.6 Million

Duluth, MN

The Black Woods Blizzard Tour celebrated its 26th anniversary February 5 - 9th at the Black Bear Casino Resort and raised **\$1,631,400** to provide support to individuals battling ALS. 260 snowmobilers rode an average of 420 miles over the 3 days, all to Fund the Fight Against ALS. The Black Woods Blizzard Tour has now raised nearly **\$21 million** in its twenty-six-year history.

Snow came in at the last minute, and riders blazed trails from Black Bear Casino Resort to Tower to Grand Rapids and back. Organizers had developed back-up plans to shorten the ride and to follow the snow to Lake Vermilion; however, riders were overjoyed when they got to snowmobile all three days as originally planned, with no trailering required.

Fun, fellowship, and laughter followed the rides each day, with entertainment provided by the comedian C. Willi Myles and the NorthWoods Band on Thursday and Friday nights. Former Minnesota Twins alumni Terry Steinbach and Kent Hrbek also participated in the three-day event.

Saturday night's sold-out Welcome Home Celebration Dinner featured a live and silent auction, as well as video messages from ALS organizations sharing how funds provided by Never Surrender Inc had advanced research, expanded access to clinical trials, and provided help for people living with ALS and their families. Kurt Martinson, of Sartell, MN, was named Rider of the Year, and long-time ALS advocate Kent Hrbek was Volunteer of the Year. A replay of the Welcome Home event is available on [www.blackwoodsblizzardtour.com](http://www.blackwoodsblizzardtour.com).

We are incredibly grateful to our sponsors that made this event possible. We would also like to thank our community for their important donations and our riders for not surrendering to Mother Nature and for Never Surrendering in our Fight Against ALS.



## **Kolar Toyota ALS Fishing Tournament to Celebrate 30th Year (May 30 & 31, 2025)**

**By: Kara Kolquist Stokke**

Thirty-ish years ago I had no idea what the letters ALS stood for and I don't think at that time I could have imagined how it would change my life in a very unexpected way! I can remember vividly that day in September of 1995 when my extended family gathered in the home I grew up in and waited for my parents to return from Mayo Clinic. My dad had been diagnosed with ALS. At 13 years old, the only thing I really wanted to know about ALS was if my dad was going to

die. I remember my grandpa looking me in the eyes and telling me, "we are all going to die at some time, we just don't know when." He told me we were going to learn everything we could about ALS and fight with my dad every step of the way, and that is exactly what my family did.

The fast progression of the disease forced our family to learn quickly. We learned about the disease process and how to care for my dad. My dad connected with other ALS patients living in MN in order to learn how to live with the disease in the most manageable way. He met ALS doctors from around the country to ensure he was doing everything he possibly could to fight this disease. He learned about research trials for ALS and signed up for everything and anything that he qualified for with an "I have nothing to lose" attitude. My dad lobbied in Washington DC with officials from the National ALS Association and met with the then MN Governor to advocate for ALS patients. He had a "no rock unturned" mentality when it came to fighting ALS.

Because there is no time to waste in fighting ALS, because the disease is so costly for patients and their family, and because there wasn't enough funding for research to make a significant impact in finding a cure, our extended family went to work and started ALS fundraising in Duluth, MN to support patients in the state of MN (and surrounding states). We started with a fishing tournament and eventually founded Never Surrender Inc, which has three events to Fund the Fight against ALS: fishing, snowmobiling, and bicycling.

The ALS Fishing Tournament was first held in June of 1996 and proved to be successful-raising money and bringing hope to the ALS community. The tournament is now known as the Kolar Toyota ALS Fishing Tournament and has raised over \$4.6 million for patient care and research since the start. This annual event was something my dad looked forward to each year as it brought so much hope and in his own words, "hope drives life!" Although my dad is no longer with us, this event continues to be important in providing other ALS patients with the hope needed to fight the ALS fight.

This year marks the 30th year of the Kolar Toyota ALS Fishing Tournament and is going to be the best year yet. All past anglers, volunteers, prize winners, and sponsors are invited back on May 30 & 31 to fish on Island Lake and attend the banquet at the University of MN Duluth. Prior to the Saturday night banquet, the community is also invited to attend our Light of Hope Conference, in which we will have leading neurologists - including one who is researching the impact of AI - take questions from the audience about the latest in ALS research.



# Never Surrender Inc.

Funding the Fight Against ALS



## WIN A NEW BOAT!



- Multiple divisions & formats
- Fish on Island Lake or virtually

**Attend the Kolar Toyota  
ALS Fishing Tournament  
kick off party to learn  
more. All are welcome!  
No RSVP required.**

March 19, 2025 | 5:30 pm  
Skyline Social and Games  
4894 Miller Trunk Hwy  
Hermantown, MN

**FOOD! DRINK!  
PRIZES!**

SCAN TO VIEW  
PHOTOS  
OF THE 2025  
BLACK WOODS  
BLIZZARD TOUR!



## Tomassoni Tour - Cycle For ALS Hopes to Raise \$300,000 in Third Year

TOWER, MN

Never Surrender's newest event, the Tomassoni Tour - Cycle for ALS, set a record for the most money raised in a second-year event last fall: \$280,506. Looking forward to this fall, the committee hopes to break \$300,000.

The Tomassoni Tour is structured similar to the Black Woods Blizzard Tour. Cyclists fundraise and are provided with a red-carpet experience: Hotel, meals, entertainment, transportation, and trail support throughout the weekend.

This year, 100 cyclists and over 40 volunteers will gather at Fortune Bay Resort Casino in Tower, Minnesota to pay tribute to the late Senator Tomassoni and to continue the good work Tomassoni started in bringing awareness and raising funds for ALS.

Terry Steinbach, a MLB World Series champ, participated in last year's tour with his wife, Mary. Terry said, "Mary and I look forward to this event because it's something that we can do together. The e-bikes make it doable for anyone and it's really a relaxing and enjoyable time for us." When asked what he would say to someone unsure about joining the tour, Steinbach said, "If I can do it, anyone can do it!"

**SAVE THE DATE: September 18-20, 2025 | Register today at [www.TomassoniTour.com](http://www.TomassoniTour.com)**

VISIT [WWW.NEVERSURRENDERINC.ORG](http://WWW.NEVERSURRENDERINC.ORG) FOR INFO ON ALL OF OUR EVENTS!

# Never Surrender's ALS LIGHT OF HOPE PANEL

Moderated by Kent Hrbek, Minnesota Twins

## HEAR FROM LEADING NEUROLOGISTS

Merit Cudkowicz, MD, MSC – Massachusetts General  
Amber Erickson, MD – Essentia Health  
Eric Rosenthal, MD – Massachusetts General  
David Walk, MD – University of Minnesota

### DISCUSSION TO INCLUDE:

- Expanded Access Protocol Program Updates
- Latest Research Developments using Artificial Intelligence
- Audience Q&A with Doctors

Join us after the panel for a program, celebrating the 30th year of Never Surrender's Kolar Toyota ALS Fishing Tournament. Learn how we funded \$2 million in ALS patient care and research last year.

5pm Social Hour | Free-Will Donation Pasta Dinner | Live & Silent Auction  
Guest Speaker | Raffle Drawing | Tournament Awards

SATURDAY, MAY 31, 2025

**4:00 PM – 5:15 PM**

UNIVERSITY OF MINNESOTA DULUTH CAMPUS  
DULUTH, MINNESOTA

## Registration

For In-Person & Virtual Attendance:  
<https://forms.office.com/r/4hZTs0P3xt>

QUESTIONS: (218) 302-1331



**FREE & OPEN TO  
THE PUBLIC**



Merit Cudkowicz, MD, MSC



Amber Erickson, MD



Eric Rosenthal, MD



David Walk, MD

## COLLABORATION BETWEEN NSI AND ESSENTIA HEALTH

### Never Surrender's New Loan Closet Initiative

Breaking news! Never Surrender has signed a contract with Essentia Health in Duluth, Minnesota to create a storage space that will house a loan closet. The location of this new loan closet is what makes it special. It will be in the Miller Hill Health Plaza, adjacent to where the weekly ALS clinic and ALS boot camp are located.

### Why is This Important?

By providing much of the equipment on-site, we will reduce the cost of shipping or delivering equipment. Currently, much of the equipment provided to people living with ALS in the Northland is shipped from the Twin Cities Metro area. This not only takes more time but also increases the cost of providing this service.

### What Does This Mean For People Living With ALS and Their Families?

This means that when people come to their ALS clinic visit or ALS boot camp and equipment needs are identified, we will often be able to provide it immediately on-site. We will also be able to show them the equipment and do training needed for safe and effective use. Providing high quality equipment in a timely manner with appropriate training for people living with ALS, will improve their quality of life and reduce the burden on care partners.

## THANK YOU!

Thank you to the Never Surrender Family for your continued support in the Fight against ALS by participating in our Kolar Toyota ALS Fishing Tournament, Tomassoni Tour and Black Woods Blizzard Tour.

If your friends or family members ask how else they can help, here are some additional ideas:

- **Donate Items** – Contribute items like gift baskets, sports memorabilia or services to help raise funds at the events. We are also always on the lookout for new items for our raffles, too – if you know a business willing to donate a big ticket item for a raffle, let us know. In the past, we have raffled off items such as: RZR's, Rangers, Winnebago, Guns, and more.
- **Volunteer Your Time** – Share your skills or lend a hand at Never Surrender events. Every hour makes a difference!
- **Make a Donation** – Your gift helps Fund the Fight against ALS. Check if your employer offers matching gifts to double or triple your impact.
- **Plan Your Legacy** – Include Never Surrender, Inc. in your estate planning to ensure the fight against ALS continues.

Get involved today! Contact us at (218-302-1331) or visit [NeverSurrenderInc.org](http://NeverSurrenderInc.org). Together we will Never Surrender to ALS!