

Join Us! *Never Surrender Inc.*

Funding the Fight Against ALS

JULY 2025
NEVER SURRENDER INC
ALS NEWSLETTER



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 29 - 30, 2026



Tomassoni Tour
September 18-20, 2025

Never Surrender Inc.

Funding the Fight Against ALS

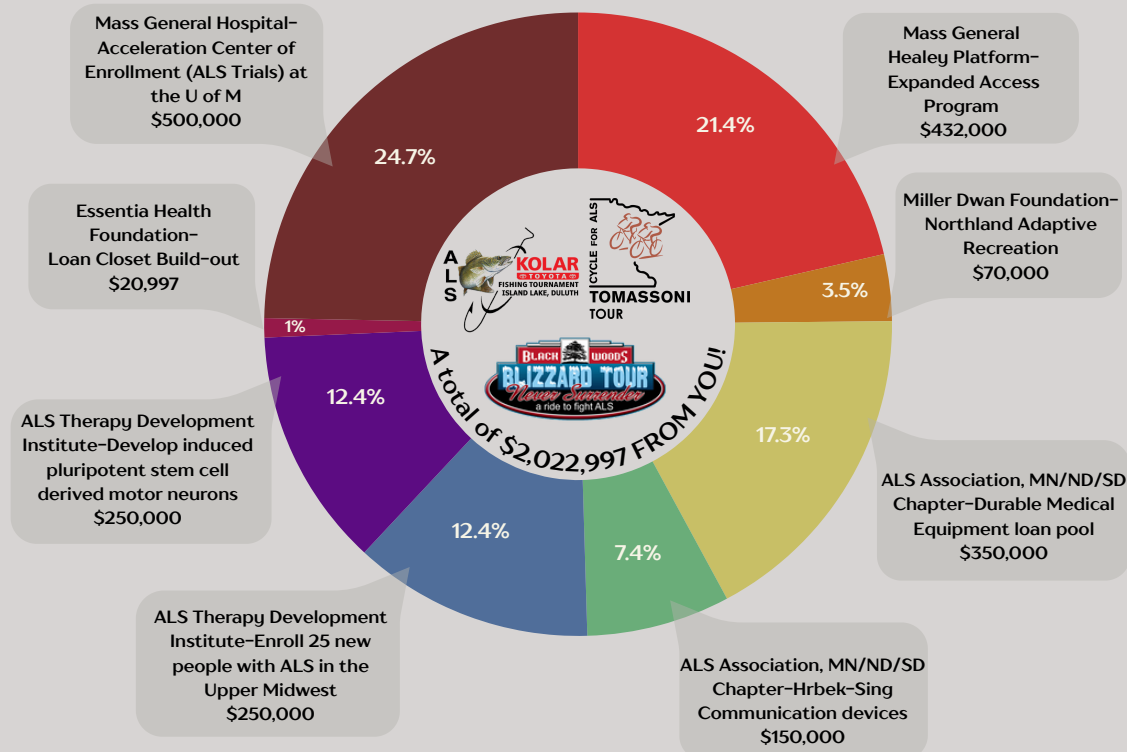
Your Funding Dollars at Work

One organization that received funding in 2024 from NSI is ALS Therapy Development Institute (TDI.) We checked in with Carol Hamilton, Senior Vice President of Development for ALS TDI, to see how the donations you raised at NSI are making a difference for people living with ALS and their families.

Never Surrender Inc is proud to support ALS TDI's ALS Research Collaborative (ARC) program. Can you tell our readers more about what the ARC is? *ARC is the longest running, and most comprehensive natural history study in ALS, with more than 45 terabytes of data from people with ALS. The ARC program partners with people living with the disease to monitor movement, vocal progression, blood-based biomarkers, and lifestyle history. While collecting blood samples, right from peoples' homes, ALS TDI can use those samples to create stem cell models of disease that can then be used to test drug candidates. ALS TDI anonymizes all of this data, and shares it with researchers across the globe, so that ALL ALS researchers can accelerate their work. The ARC has the potential to reveal new risk factors for ALS - and potential avenues for treatment. Multiple findings and publications have already come from this program, making it critical to the research community's understanding of the disease. The overriding goal of the program is to accelerate the discovery of treatments for ALS by better understanding the disease's underlying biology.*

Part of the funding that NSI provided was to help enroll people living in MN, WI, SD, IA, ND. What progress has been made with enrollment? *We are very proud to report, that since this grant was approved in 2024, we have been able to increase our enrollment rate by 3X in the 5 states the grant focused on: MN, WI, SD, IA, ND. And, nationally, we have increased enrollment by more than 200 people living with ALS.*

The Black Woods Blizzard Tour, Kolar Toyota ALS Fishing Tournament & Tomassoni Tour-Cycle for ALS allowed Never Surrender Inc to donate the following in 2024:



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



30th Annual Kolar Toyota Fishing Tournament Reels in Record \$\$ Amount Duluth, MN

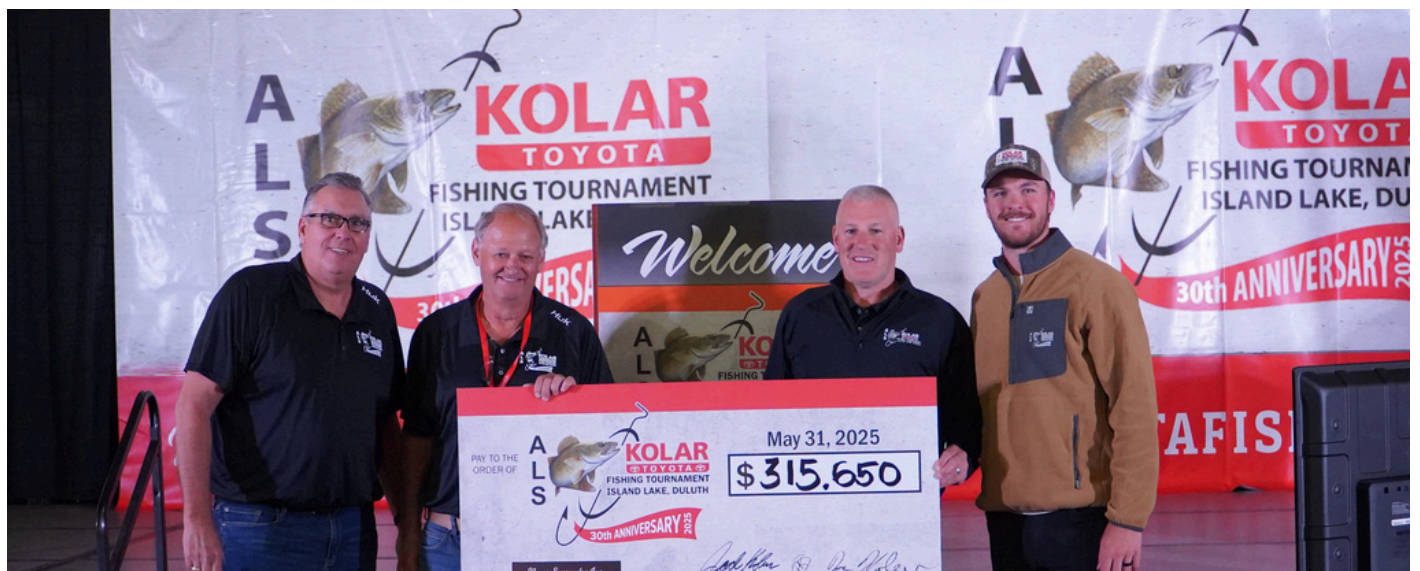
The 30th annual Kolar Toyota ALS Fishing Tournament broke a new record this year by raising over \$324,000. This brings the all-time amount raised to \$4.9 million to fund the fight against ALS! This event is the event that started the legacy of Never Surrender Inc, a non-profit based in Duluth, MN.

Just ahead of the awards dinner, Never Surrender Inc hosted its second Light of Hope ALS Panel Discussion in two years. Four leading neurologists shared an overview of the work they are doing to help people living with ALS as well as what is happening on the forefront of ALS research, including artificial intelligence and how it is changing medicine. Merit Cudkowicz, MD, MSC and Eric Rosenthal, MD came from Massachusetts General Hospital. They were joined by David Walk, MD from the University of Minnesota and Amber Erickson, MD from Essentia Health. All four doctors answered questions from attendees.

There were 109 two-person teams fishing on Island Lake, while 5 people fished in the virtual tournament. Top finishers include first time walleye stringer champions, John Yankowiak of Duluth and teammate Cory Nelson of Barnum. This duo caught six fish, totaling 125.00 inches of walleye. The single longest walleye was also caught by Yankowiak and Nelson. Kraig and Hayden Anderson of Superior kept their crown from last year for catching the longest stringer of 5 bass. Their tally was 97.0 inches of fish. This father - son duo also caught the longest single bass which was 20.25 inches long.

Anglers fundraise throughout the year in support of those who are living with ALS. The event's silent and live auctions as well as crucial support from sponsors contributed to the event's success.

Event organizers extend their gratitude to the community and surrounding areas. With the funds raised, Never Surrender Inc will be able to continue to fund first-class ALS treatment trials, research and direct care support to individuals and families.





Tomassoni Tour - 3rd Annual Bike Tour

Why I Ride - By: Todd Lauer

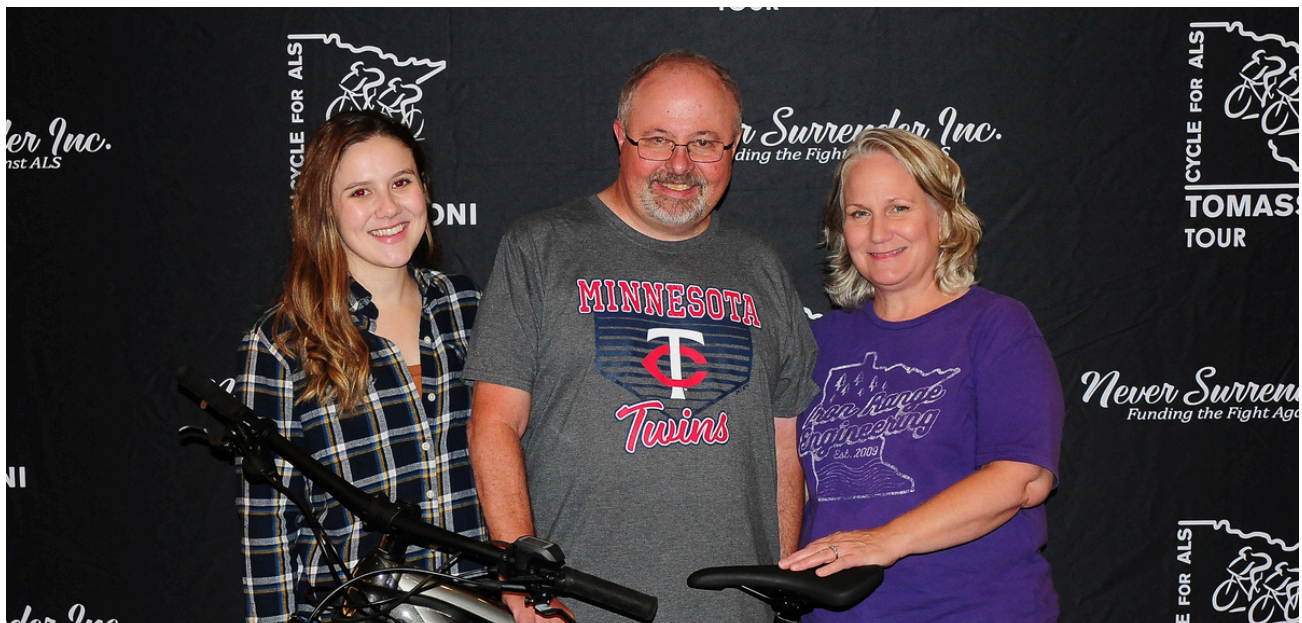
I was diagnosed with ALS in 2015. I have seen and experienced the destruction ALS causes to individuals living with ALS, their families, and their care teams.

The idea for the Tomassoni Tour originally came from an ALS clinic appointment. Dr. Erickson was telling us about a local group that had raised money for ALS through a motorcycle ride. She then challenged us and said, "What are you going to do?" This statement bothered me greatly. When we got home my wife Jen said, "You know, a bike ride would be a great ALS fundraiser."

Fast forward a couple of years to when David Tomassoni had been diagnosed. He visited our home a couple of times to talk about life with ALS. The last time he left, Jen said again "A bike ride would be a great ALS fundraiser."

The next day I called my friend Ardy who ran the Mesabi Trail Tour for the last 18 years and asked what she thought of the idea. She was positive about it and thought it would work well. My next call was to David Kolquist, Never Surrender's President. It took a few phone calls to convince him of the idea before he agreed to do a pilot year. I knew if they tried it once, the ride would be a success.

ALS is an indiscriminate disease. Any one of us could get it at any time, and the disease is becoming more prevalent. I ride in hopes of finding a cure so that none of our children will have to deal with this horrible disease in the future. I believe that finding a cure for ALS is similar to eating an elephant: one bite at a time. With each of us doing a small part, I believe the ALS elephant will be eaten and the cure will be found.



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).

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/>

Access for ALL in ALS

Funded by the NIH/NINDS, the Access for ALL in ALS Consortium (ALL ALS), is a community of two coordination centers and 35 research sites across the United States, conducting a combined longitudinal natural history study and biomarker collection study for ALS. This study will include both people currently living with ALS, and asymptomatic ALS gene carriers. Contact us for more information at cnru@umn.edu.

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 auctions, too – if you know a business willing to donate an item, let us know.

-**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. Together we will Never Surrender to ALS! info@neversurrenderinc.org



Registration is Open to the Public

Visit

www.BlackWoodsBlizzardTour.com

Contact Sandy with questions:
Sandy@NeverSurrenderInc.org

This 3-day snowmobile ride is for experienced riders covering up to 150+ miles per day.