Never Surrender Inc. Funding the Fight Against

First Platform Trial for ALS Comes to Duluth

For Immediate Release

January 26, 2022

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The HEALEY ALS Platform Trial, designed to evaluate multiple ALS treatments simultaneously, is now available to those with ALS in the Northland, thanks to a partnership between Massachusetts General Hospital and Essentia Health in Duluth.

The HEALEY ALS Platform Trial is the first platform trial in the world for ALS, not only providing hope for those in the Northland with the disease, but also accelerating the development of effective and breakthrough treatments for people living with ALS. Essentia Health is one of several facilities participating in the trial nationwide, allowing those with ALS locally to receive the latest treatments and the most up-to-date care.

"What's unique is that we test multiple drugs in the same trial," says Merit Cudkowicz, MD, principal investigator and sponsor of the HEALEY ALS Platform Trial, director of the Sean M. Healey & AMG Center for ALS and chief of the Department of Neurology at MGH, and the Julieanne Dorn Professor of Neurology at Harvard Medical School. "We can add drugs with an amendment very fast, we share the placebo groups so that more people are on the active treatments, and we can drop treatments that aren't working. This is much better for people with ALS."

The HEALEY ALS Platform Trial has received funding from Never Surrender, Inc., a Duluthbased organization formed specifically to raise money to fight ALS, including the Black Woods Blizzard Tour and the Kolar Toyota ALS Fishing Tournament. In 2021, snowmobilers and anglers in Never Surrender Events raised more than \$1.5 million for ALS research and patient care.

"We're excited for the opportunity to bring the HEALEY ALS Platform Trial to people fighting ALS in the Northland," says Dr. Amber Erickson, Section Chair-Neurology and Medical Director for the ALS Association Recognized Treatment Center at Essentia Health in Duluth. "We have an excellent team at our ALS clinic, however the one thing that we have not been able to offer those living with ALS is the opportunity to participate in research. The generosity of people right here in our community is already making a huge difference in the lives of people with ALS and their families, both here in Duluth and in the surrounding area, and this can really take it to the next level in providing excellent ALS care."

"When we started our fundraising events more than 25 years ago, there were few treatments for ALS," said Never Surrender President David Kolquist. "The HEALEY ALS Platform Trial is exactly what we've been waiting for all these years. On behalf of our Black Woods Blizzard Tour riders and our Kolar Toyota Fishing Tournament anglers, we're proud to support Dr.

Cudkowicz and the HEALEY Platform Trial, and pleased to do our part in bringing this groundbreaking opportunity to those with ALS in the Northland."

Never Surrender's 2022 Black Woods Blizzard Tour begins in Proctor on Thursday February 3rd and runs through Saturday February 5th with 250 riders. Those wishing to support Tour riders and their efforts to raise money to fight ALS can visit <u>www.blackwoodsblizzardtour.com</u>.

Amyotrophic Lateral Sclerosis (ALS) is a progressive neurodegenerative disease that affects nerve cells in the brain and spinal cord. ALS usually strikes people between the ages of 40 - 70, but it can strike anyone at any time. Currently, treatment options are few.

For More information on the Sean M. Healey & AMG Center for ALS at Massachusetts General Hospital, visit <u>www.MassGeneral.org/HealeyCenter</u>.

<u>Never Surrender, Inc.</u> is a Duluth-based 501c3 organization, focusing on charitable activities for the purposes of raising money to fund ALS research, as well as help people with ALS and their families.

A detailed news release will be provided at the time of the briefing. Call Ray Higgins (218-591-2692) or David Kolquist (218-348-6911) with any questions.