



KrabbeConnect
CONNECTING PATIENTS & RESEARCH

2022 CALENDAR OF EVENTS AND ACTIVITIES

RARE DISEASE DAY - FEBRUARY 28TH, 2022

February 28th, 2022 is Rare Disease Day! At KrabbeConnect, we encourage you to use the entire month of February to share your story or participate in an activity that advances awareness about the 300 million people living with a rare condition.

#CUREKRABBE PORTLAND TO PORTLAND CHALLENGE MAY 1 - 31ST, 2022

Are you up for a challenge? Our community of patients are challenged each day due to their Krabbe disease diagnosis. For 31 days, we ask you to select your favorite way to log miles. You can run, bike, swim, walk, or pick another form of purposeful movement to help #curekrabbe!

#CUREKRABBE ANNUAL MEETING - JUNE 24TH-25TH, 2022

In partnership with ULF, we're thrilled to offer a half day meeting to keep patients and caregivers abreast of important information, new programs and resources, industry updates, and valuable projects. More to come on this important Krabbe disease family gathering at Eaglewood Resort and Spa in Itasca, IL

A MILLION DREAMS GALA - AUGUST 19TH, 2022

KrabbeConnect invites you to join us for an evening dedicated to raising critical dollars and advancing awareness for Krabbe disease at the Radisson Blu in Bloomington, MN. We hope you join us at this special event to learn, connect with patients living with Krabbe disease, and to help #curekrabbe.

BRAVERY FOR AVERY GOLF TOURNAMENT - AUGUST 28TH, 2022

The Coupe family has arranged a Family-Advised Fund in honor of their daughter, Avery, who lost her battle to Krabbe disease in May of 2020. Their fundraising efforts will go towards advancing research to help #curekrabbe. Email us at info@krabbeconnect.org to see how you can be a part of their event.

SEPTEMBER LEUKODYSTROPHY AWARENESS T-SHIRT DRIVE

Are you or someone you know a Krabbe disease hero? Add your Krabbe disease hero's name to our Leukodystrophy Awareness T-Shirt. All proceeds from this fundraiser will help support the #curekrabbe programs at KrabbeConnect. Keep an eye on the events page, the link will be available in July 2022.



Giving Tuesday is November 29th, 2022-KrabbeConnect Year-End Annual Campaign will run November 15th, 2022-December 31st, 2023. Thank you for remembering KrabbeConnect on this national day of giving.