

RESEARCH

- KrabbeCURES (Community United Research & Engagement Study)-an opportunity for patients and caregivers to contribute to research through a worldwide database tracking the demographics of patients affected with Krabbe disease to help inform future projects. Enroll in KrabbeCURES on KrabbeConnect.org
- Clinical Trial Updates-equip patients and caregivers with clinical trial information, and provide resources to help navigate and learn about the new therapies.

KrabbeConnect.org

PHONE

1-800-800-5509



EMAIL

info@krabbeconnect.org



krabbeconnect.org/donate/



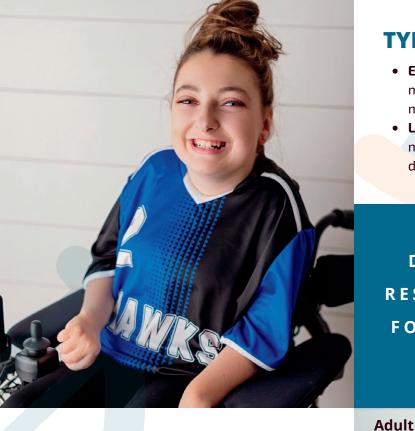
ADDRESS

PO Box 254 Rosemount, MN 55068



Working towards a day in which each patient receives an early diagnosis, has access to state-of-the-art care, and lives a life free of Krabbe disease

KrabbeConnect CONNECTING PATIENTS & RESEARCH



OUR MISSION & COMMITMENT

To be the source of comprehensive and upto-date resources for patients living with Krabbe disease & their caregivers through our commitment to connecting patients to the science and the science to the patient. Working collaboratively with key stakeholders will bridge and strengthen the gaps to assure a better life for patients living with Krabbe disease.

OUR HEROES

Tell us about your hero? We invite you to visit KrabbeConnect.org to have your hero featured on our website.

TYPES OF KRABBE DISEASE

- **Early-infantile:** Onset between 0 to 13 months. This is the most common and most severe form of Krabbe disease.
- Late-infantile: Onset between 13 to 36 months presenting with vision disturbance, slurred speech, abnormal gait.



Early Infantile

SIGN UP FOR KRABBECURES

LESS COMMON

DRIVE

RESEARCH

FORWARD

- **Juvenile**: symptoms present between 3 to 16 years of age.
- Adult-onset: this type surfaces later in childhood, adolescence, or even adulthood.

Details at KrabbeConnect.org



RESOURCES

- **Patient Support Team** Let us connect you with an easy-to-talk to parent, sibling, or grandparent who is experienced with the Krabbe disease journey.
- **Patient Assistance Program**-offers patients and caregivers support by helping ease the financial burden of Krabbe disease.
- **Partner with Us Program**-A unique program to help families establish a donor advised fund to aid impactful efforts in Krabbe disease.
- Patient Journey & Resources Maps-Resources to help newly diagnosed patients, families, caregivers and their care teams the ability to quickly navigate resources and treatments available.
- Webinars-videos to keep patients, caregivers, industry partners, and the medical community informed of important information.
- Newborn Screening (NBS)-learn about newborn screening for Krabbe disease and check out the map to see the growing number of states screening.
- **#curekrabbe Shop** Join in the movement to increase awareness of Krabbe disease by purchasing apparel and gifts.