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](http://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.

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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
**OUR MISSION & COMMITMENT**

To be the source of comprehensive and up-to-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.

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

**RESOURCES**

- **KrabbeConnect Advocates** - 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.