KrabbeConnect
CONNECTING PATIENTS & RESEARCH

KRABBE DISEASE PATIENT JOURNEY

STEP 1 Diagnosis

SYMPTOMATIC PATHWAY

- Patient presents with clinical symptoms
- Lab tests needed to confirm patient diagnosis and parent's gene mutation/variant for Krabbe disease (genetic test)

PRE-SYMPTOMATIC PATHWAY

- Identified via newborn screening state lab test
- Prior family history of Krabbe disease
- Lab tests needed to confirm patient diagnosis and parent's gene mutation/variant for Krabbe disease (genetic test)

STEP 2 Connect with Krabbe Disease Expert

krabbeconnect.org

- Patient undergoes additional testing to determine type of Krabbe disease
- Determine eligibility for treatment
- Krabbe disease expert and family discuss evaluation results to determine treatment options and management of disease

STEP 3 Krabbe Disease Management

Supportive Care

- Establish a Primary Care Physician
- Establish a care team and support system
- Inquire with social workers and physicians about funding sources for out-of-pocket medical expenses
- Learn about Krabbe disease from reputable resources
- Stay informed about clinical trials and treatments

Treatment

- A bone marrow or cord blood transplant may stabilize disease progression
- Transplant may improve outcomes in patients if treatment begins before onset of symptoms
- Clinical Trials and new therapies may provide other treatment options. Stay informed at krabbeconnect.org

Monitoring

Depending on disease type, patients may need to be evaluated routinely for disease progression