Diagnosis
- Identified via newborn screening state lab test
- Prior family history of Krabbe disease

STEP 1
Lab tests needed to confirm patient diagnosis and parent’s gene mutation/variant for Krabbe disease (genetic test)

STEP 2
- Patient undergoes additional testing to determine type of Krabbe disease
- Determine eligibility for treatment

Connect with Krabbe Disease Expert
krabbeconnect.org

STEP 3
- Krabbe disease expert and family discuss evaluation results to determine treatment options and management of disease

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

KRABBE DISEASE PATIENT JOURNEY
STEP 1
Patient presents with clinical symptoms
Step 2
Lab tests needed to confirm patient diagnosis and parent's gene mutation/variant for Krabbe disease (genetic test)
Step 3
Krabbe disease expert and family discuss evaluation results to determine treatment options and management of disease

SYMPTOMATIC PATHWAY
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)

Patient undergoes additional testing to determine type of Krabbe disease
Determine eligibility for treatment

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STEP 2
Krabbe Disease Expert and family discuss evaluation results to determine treatment options and management of disease