



LEUKODYSTROPHY & NEWBORN SCREENING AWARENESS MONTH

MEET BELLE MENNE



"Newborn Screening for Krabbe disease is still needed in MN. If Belle was identified with this disease in the first few days of life, she would have undergone a transplant much earlier in the disease progression. Intervention at the earliest point in this disease offers the best outcomes and highest quality of life to those impacted."

Carrie Menne, Belle's Mom

Carrie and Eric Menne were thrilled to welcome their daughter, Isabelle, into their lives. As she grew and developed they began to notice that she was losing milestones and began to seek answers. Finally, at fifteen months, Belle was diagnosed with Krabbe Disease. The neurologist that gave the diagnosis didn't know much about Krabbe Disease; he told them that Krabbe would take Belle's life by age three and that they should go home and enjoy the time they had left with her. Thankfully, Carrie and Eric brought up the possibility of a transplant -because of their research and diligence, Belle was transplanted successfully.

Today, Belle is an amazing, smart, funny, and caring young adult. She loves math and was on the dean's list at college last year. She is a season ticket holder for the MNUFC soccer team. Belle loves the sun and being at the cabin.



In 2020, there were **63,443** live births in Minnesota ²



Number of conditions screened for in MN ³

NBS IN MINNESOTA

All babies in the United States are screened for several conditions shortly after birth. Approximately 24-48 hours after a baby is born in the United States, the heel is pricked by a nurse to collect a small sample of blood. Afterward, the nurse puts a series of blood drops onto a filter paper to create several "dried blood spots." Next, the newborn screening card is sent to the state laboratory for analysis.

The MN NBS committee voted unanimously in June 2023 to add the condition to the state's Newborn Screening panel and they are beginning the process of adding Krabbe disease.

WHY SCREEN FOR KRABBE?

Krabbe disease is a severe neurodegenerative and rapidly progressing condition requiring immediate treatment for the most severe forms. Belle was diagnosed with a later onset form of Krabbe disease allowing her family additional time to navigate treatment. However, the medical issues and symptoms of any form of Krabbe disease are significant and life-impacting. A delayed diagnosis, especially in the most severe forms, equates to palliative and supportive care as the only means of treatment until premature death.

WHAT IS KRABBE DISEASE?

Krabbe disease (pronounced krab A), is a rare genetic disorder, also known as globoid cell leukodystrophy. In the United States, Krabbe disease has been reported to affect approximately 1 in 100,000 individuals.¹ Infantile Krabbe disease is the most common and severe form causing infants to lose the ability to eat, extreme irritability, inability to sit up, and grasp objects, blindness, and seizures. Sadly, infants die within the first 2-3 years of life in states that do not test for Krabbe disease.

We invite you to learn more at KrabbeConnect.org.



*All information in this fact sheet is based on data available before 9.22.2022

This project was supported by the following:





KRABBE DISEASE IN MINNESOTA

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RESOURCES

- The Leukodystrophy Newborn Screening Action Network is dedicated to advancing newborn screening for leukodystrophies and lysosomal storage disorders, supporting newly-diagnosed families, and ensuring collaboration between all stakeholders. Learn more at <https://ldnbs.org/>.
- CDC offers funding and assistance through the Newborn Screening Quality Assurance Program (NSQAP). More information can be found at <https://www.cdc.gov/labstandards/nsqap.html>.
- Baby's First Test provides funding opportunities through grants. Learn more at <https://www.babysfirsttest.org/newborn-screening/funding-opportunities>.
- American Public Health Laboratories NewSTEPS program provides data, technical assistance, and training. Details at <https://www.newsteps.org/>.
- KrabbeConnect offers patient support services to help families navigate the burden of Krabbe disease. Learn more at <https://krabbeconnect.org/>.
- Hunter's Hope Foundation is a non-profit organization committed to giving hope through education, awareness, research, and family care for all leukodystrophies. Learn more at <https://www.huntershope.org/>.

CITATIONS

1. Wenger DA. Krabbe Disease. 2000 Jun 19 [Updated 2011 Mar 31]. In: Pagon RA, Adam MP, Ardinger HH, et al., editors. GeneReviews® [Internet]. Seattle (WA): University of Washington, Seattle; 1993-2017.
2. "Fertility Rate: Ohio, 2010-2020." March of Dimes | PeriStats, <https://www.marchofdimes.org/peristats/data?reg=99&top=2&stop=1&lev=1&slev=4&obj=1&sreg=27>. Accessed 22 Sep. 2022.
3. "Minnesota | Baby's First Test | Newborn Screening | Baby Health." Babysfirsttest.org, 2015, www.babysfirsttest.org/newborn-screening/states/minnesota. Accessed 22 Sept. 2022.