State Fact Sheet

KRABBE DISEASE IN OHIO

LEUKODYSTROPHY & NEWBORN SCREENING AWARENESS MONTH

MEET LENNON FOSTER

> **“Krabbe disease Newborn Screening is an absolute must. I am so incredibly grateful Lennon was born in Ohio.**
>
> **I cannot imagine being a parent to a child with Krabbe disease who did not have access to early screening. Our family has the opportunity to enjoy Lennon for many years when many don't.”**
>
> Brandy Foster
> Lennon's mom

Brandy Foster will never forget the phone call she received when her daughter, Lennon, was a few days old - a call that changed everything. A genetic counselor from Nationwide Children’s Hospital called to tell them that Lennon’s Newborn Screening had come back with an abnormal result and immediate follow-up testing was needed. She mentioned that there was a possibility that Lennon had Early Infantile Krabbe disease and advised them to not use the Internet to learn more about it.

During the call, Brandy learned that Ohio had only begun screening for Krabbe nine months prior and was the fourth state to do so. Just three days later, Lennon received a confirmed diagnosis of Krabbe disease, and life-saving decisions had to be made quickly.

Lennon received a stem-cell transplant at Nationwide Children’s Hospital within the first weeks of her life. Brandy acknowledges that the transplant process was challenging but that it was worth it. She urges parents in this situation to educate themselves and make decisions as quickly as possible because every second matters.

Today, Lennon is growing and learning; she loves taking walks, driving her car outside, and watching movies.

In 2020, there were
129,191 [2]
live births in Ohio

38

Number
of conditions
screened for in OH [3]

NBS IN OHIO

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.

Ohio began screening for Krabbe disease in 2016.

WHY SCREEN FOR KRABBE?

Krabbe disease is a severe neurodegenerative and rapidly progressing condition requiring immediate treatment for the most severe forms. The medical issues and symptoms 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**.

KrabbeConnect
CONNECTING PATIENTS & RESEARCH

*All information in this fact sheet is based on data available before 9.9.2022

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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=39. Accessed 6 Sep. 2022.
3. "Minnesota | Baby's First Test | Newborn Screening | Baby Health." Babysfirsttest.org, 2015, https://www.babysfirsttest.org/newborn-screening/states/ohio. Accessed 6 Sept. 2022.

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