KRABBE DISEASE IN IDAHO

State Fact Sheet

LEUKODYSTROPHY & NEWBORN SCREENING AWARENESS MONTH

MEET GRAYSON MORSE

"Newborn Screening would have given us knowledge and choices that we didn't have without it."

Piper Morse,
Grayson's Mom

Grayson was born on October 30, 2015, bringing more joy and love into his parents' lives than they could ever imagine. Everything was seemingly normal until he was around four months old: Grayson started becoming more irritable, having trouble nursing, and losing the milestones he had started to gain. The doctors had thought he had reflux and he spent almost a month in the hospital for weight loss and dehydration.

Grayson's mom, Piper, used the internet to search for causes for hand tightening and the word Krabbe appeared. She pushed that thought aside because it was so rare and she assumed that it couldn't happen to them, but the word remained in her mind.

After Piper fought for answers, his pediatrician helped to get him the emergency MRI that he needed; the MRI showed a loss of white matter in his brain. It wasn't until the next morning that Grayson's parents received the worst news of their lives. The neurologist didn't seem to be upset when she came in to speak with them, so Piper had a moment of relief, thinking it must not be anything serious. Unfortunately, that was not the reality: she informed them that he had Krabbe disease and the life expectancy was two years. Piper collapsed in the bathroom knowing she was going to lose her baby and there was nothing she could do. The hospital gave no hope or treatment options - only a grim prognosis.

Thankfully, a family member found Dr. Maria Escolar's information and they traveled to Pittsburgh three days after diagnosis to see if he was eligible for a stem-cell transplant. One month later, he received the transplant that has prolonged his left and preserved many of his abilities - the most famous one being his smile.

Grayson is now seven years old and is a happy little boy. He loves to watch the show *Word Party* and plays with his switch-activated toys and pianos. He especially loves when people sing to him and often joins in. Grayson has an infectious belly laugh and inspires those around him by his sunny disposition.

Newborn Screening would have changed everything for Grayson. It would have given him the chance to crawl, walk, talk, and Piper could have heard him call her Mama.

KrabbeConnect
CONNECTING PATIENTS & RESEARCH

*All information in this fact sheet is based on data available before 7.31.2023

NBS IN IDAHO

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 blood sample. 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.

Idaho is not screening for Krabbe disease.

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 very 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**.

In 2020, there were [2]
21,533
live births in Idaho

52

Number [3]
of conditions screened
for in Idaho

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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: Idaho, 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=34. Accessed 13 August 2023.
3. "Idaho| Baby's First Test | Newborn Screening | Baby Health." Babysfirsttest.org, 2015, https://www.babysfirsttest.org/newborn-screening/states/idaho. Accessed 13 August 2023.

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