KRABBE DISEASE IN UTAH

State Fact Sheet

LEUKODYSTROPHY & NEWBORN SCREENING AWARENESS MONTH

MEET TAITEN BUTTERFIELD

"Newborn Screening would have enabled us to prepare better and hold our son longer."

Kayla Butterfield
Taiten's Mother

Weldon and Kayla Butterfield were overjoyed to welcome their son, Taiten, into their lives. He was a happy baby and laughed often. Taiten loved going for walks outside, camping, watching his dogs, and listening to bedtime stories. When Taiten was a few months old, everything changed and his parents knew something was wrong with their son. After various tests were performed, they were handed a diagnosis: Krabbe disease.

The neurologist couldn't look at them as the diagnosis was delivered; he handed them a pamphlet about the condition and wrote the word Krabbe on the whiteboard. He explained how Krabbe disease affects the body, what they could expect in the future, and the steps they should take. That day, Weldon and Kayla found out that their seven-month-old son was dying. They made the most of the time they had left and said goodbye to Taiten eight months later. He was only fifteen months old.

When asked about the impact Newborn Screening would have had on their lives, they replied: "Newborn Screening would have enabled us to prepare better and hold our son longer."

In 2020, there were [2]
45,702
live births in Utah

53

Number [3]
of conditions
screened for in Utah

NBS IN UTAH

All babies born 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, a nurse pricks the heel 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.

Utah is not currently 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**.

KrabbeConnect
CONNECTING PATIENTS & RESEARCH

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

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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: Utah, 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=49&creg. Accessed 31 July 2023.
3. "Utah| Baby's First Test | Newborn Screening | Baby Health." Babysfirsttest.org, 2015, https://www.babysfirsttest.org/newborn-screening/states/utah. Accessed 31 July 2023.

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