



KRABBE DISEASE IN VIRGINIA

LEUKODYSTROPHY & NEWBORN SCREENING AWARENESS MONTH

MEET DAWSON FELDT



"Newborn Screening would have given us more time with Dawson. Transplant is not a cure and is not an easy treatment; however, it does provide a good quality of life."

Alex and Kasey Feldt,
Dawson's parents

On July 16, 2019, Alex and Kasey Feldt welcomed a perfect baby boy, Dawson Luke Feldt. He was beautiful, strong, and everything they had dreamed of. They had three perfect months of smiles, babbles, and a couple of laughs until they noticed Dawson lacked head control, was consuming less formula, and seemed to have an increased difficulty keeping his formula. Even though Alex and Kasey did not want to believe something was wrong with Dawson, they consulted with a neurologist. While conducting tests for months to find answers, he started having spasms which caused incredible nerve pain, and was rapidly losing weight. After a weeklong hospital stay, Alex and Kasey learned Dawson had Krabbe disease. Over the phone, the neurologist described the unpleasant symptoms of the disease, and that the life expectancy would only be two years old. Sheer devastation consumed Alex and Kasey.

Alex and Kasey worked diligently to make Dawson as comfortable as possible. In a matter of months, they went to UPMC twice, first to meet Dr. Maria Luisa Escobar and second to have Dawson's G-Tube and Nissen surgery. After that, their lives revolved around medicine and feeding schedules, medical equipment, learning about the disease, and spending quality time with Dawson.

They took multiple family pictures, spent time in the pool, took him to the zoo, and spent every weekend with family members and friends. They tried to keep him happy and comfortable, and they soaked up every snuggle they possibly could. He loved watching Baby Shark and Mickey Mouse Clubhouse.

Dawson lost his battle with Krabbe disease on November 8, 2020, with Alex and Kasey by his side.



In 2020, there were **94,749** live births in Virginia ²



Number of conditions screened for in VA ³

NBS IN VIRGINIA

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.

Several families have worked to inform the Virginia NBS Advisory Committee about the need to test for Krabbe disease, including the Feldts. In 2020, the Virginia NBS Advisory Committee voted against adding it to their state's panel.

WHY SCREEN FOR KRABBE?

Krabbe disease is a severe neurodegenerative and rapidly progressing condition requiring immediate treatment for the most severe forms. Dawson was diagnosed with an early onset form of Krabbe disease which requires an early diagnosis to ensure treatment occurs within the first 30-45 days of life. 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 9.9.2022

This project was supported by the following:





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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=51>. Accessed 6 Sep. 2022.
3. "Minnesota | Baby's First Test | Newborn Screening | Baby Health." Babysfirsttest.org, 2015, <https://www.babysfirsttest.org/newborn-screening/states/virginia>. Accessed 6 Sept. 2022.