



# LEUKODYSTROPHY & NEWBORN SCREENING AWARENESS MONTH

## MEET MILA LEBOW



**“Newborn Screening would have given Mila a fighting chance against Krabbe Disease as treatments would have been an option. Instead, we were left helpless, forced to watch Mila decline.”**

Rachel Lebow,  
Mila's mom

Mila was born in September 2017 to parents Rachel and Wes in Virginia; however, she now resides in Florida. After a few months, they began to suspect that Mila might have some developmental delays and began to pursue answers. The answers that came were completely unexpected: eleven-month-old Mila had Krabbe disease.

The news was delivered in person by a pediatric neurologist and a neurology nurse practitioner who tried to answer their many questions as Rachel and Wes struggled to accept this new reality with tears running down their faces. The Lebows had never heard of Krabbe disease or Leukodystrophy until that very moment, and they knew that their life had just changed forever.

Today, Mila loved to be in the water to swim or bathe. She loved to be held, read, and sung to, and do activities with her brother and other children. Mila was a typical five-year-old girl with a love for princesses, Minnie Mouse, Daisy Duck, the colors pink and purple, Disney songs, and Bluey. She strongly disliked slimy feeling things and finger paint on her hands.

The Lebows are strongly in favor of Krabbe disease Newborn Screening nationwide. If Mila had been born in one of the states currently testing for Krabbe disease, her life would have looked much different. Instead, she passed away in July 2023, two months before her sixth birthday.



In 2020, there were  
**209,671**<sup>2</sup>  
live births in Florida



Number  
of conditions<sup>3</sup>  
screened for in FL

## NBS IN FLORIDA

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.

Florida does not currently screen for Krabbe disease. Its Newborn Screening program tends to only add conditions that are included on the federal Recommended Uniform Screening Panel (RUSP).

## WHY SCREEN FOR KRABBE?

Krabbe disease is a severe neurodegenerative and rapidly progressing condition requiring immediate treatment for the most severe forms. Mila was diagnosed with an early onset form of Krabbe disease at eleven months of age. This form, known as infantile Krabbe disease, requires treatment within the first 30-45 days of life. If Mila had been identified at birth with Krabbe disease, Mila could have undergone a stem cell transplant. Due to her delayed diagnosis palliative and supportive care were her only means of treatment.

## 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.<sup>1</sup> 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](https://KrabbeConnect.org).



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



## KRABBE DISEASE IN FLORIDA

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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

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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=12>. Accessed 22 Sep. 2022.
3. "Minnesota | Baby's First Test | Newborn Screening | Baby Health." Babysfirsttest.org, 2015, <https://www.babysfirsttest.org/newborn-screening/states/florida>. Accessed 22 Sept. 2022.