

05 February 2024

The Honorable Joseline A. Pena-Melnyk
Chair, House Health, and Government Operations Committee
Room 241, House Office Building
Annapolis, MD 21401

Subject: HB096 Health - Newborn Screening Program - Krabbe Leukodystrophy

My name is Jessica Blackwell and I am Lily Smith's aunt; her mom is my sister Kathleen. I am writing this with the intent to support the passing of a law that would add Krabbe testing to the newborn screening that is performed in the state of Maryland. Lily is our family's little angel. She was a happy and healthy baby until she was 6 months old and started exhibiting symptoms of Krabbe. We did not know what it was at the time but her momma knew something was not right and they received a diagnosis from Children's National Hospital. The doctors there told her parents to take her home and enjoy the time they had left while making her comfortable because she would not live past her first birthday. Her parents were fighters and found a very specialized transplant protocol through Children's Hospital of Pittsburgh that would hopefully stop the progression of the disease. While this transplant did stop the progression of the disease, she would never regain what had been lost during those first six months when no one knew she had Krabbe because it is not part of the newborn testing in Maryland.

Because of the lack of testing in Maryland, Lily is wheelchair bound with a feeding tube and a trachea and requires constant care. Because there is no testing in Maryland Lily has celebrated her first, tenth and twelfth birthdays in hospitals rather than at Chuck E. Cheese playing with friends. Because there is no testing in Maryland, Lily cannot ride a bike or run outside like other 12 year old children. Because there is no testing in Maryland, Lily cannot attend school and play during recess; instead she works harder than any person I know to be able to hold her head up and try to communicate through an eye gaze device, the only part of Lily's body that she has control over. If Lily had been born in a state that included Krabbe as part of their newborn screening, she would have a completely different life. If Krabbe had been included in Maryland's newborn screening when Lily was born, she could have had the transplant that stopped the progression of the disease right after birth and she would be running around and riding a bicycle like other young children.

I do not understand why Maryland has not added Krabbe to newborn screening. I came here ten years ago asking for the same thing – add Krabbe to newborn screening in the state of Maryland and still nothing has been done. If adding this screening can save even one child and one family from experiencing the pain and hardships that Lily and her family experience on a daily basis then I do not understand how the state of Maryland can vote against including this testing as part of newborn screening.

Respectfully,

Jessica A. Blackwell