February 15, 2024

Shoemaker Family
1811 Hatfield Rd
Huntingtown, MD 20639

Senate Bill 117
Finance Committee
East Miller Senate Building, Room 3
Annapolis, MD

Dear Senate and Finance Committee Members,

My name is Melissa Shoemaker, our family has been forever changed by the choice the state of Maryland has made to not screen newborns for Krabbe Leukodystrophy at birth. My son Parker Eugene was robbed at his opportunity for lifesaving treatment by being born in Maryland versus another state that screens for Krabbe Leukodystrophy at birth as a standard practice. Although not a curable disease, there is treatment for Krabbe especially if diagnosed early, before becoming symptomatic through Newborn Screening. My family was not given the choice to treat him as he was already affected by the disease and presented symptoms at the time of diagnosis. I have met children that were born with the same disease as my son, who are breathing, talking, laughing, walking, and living all the wonders of an ordinary normal wonderful life. It is truly heartbreaking to know what we now know about life saving early detection.

When asked to testify I was both honored and fearful. Our family has attempted and failed on many occasions to persuade the state to take into consideration all the research, facts, and real-life witnesses. Reliving our life with Parker is so beautiful and yet so very painful. Our story will hopefully help someone in this room, and that is what is most important to us and Parker's legacy. Knowing that this bill could save a family the pain and suffering of the wisdom discovered too late, the months of not knowing what is wrong with their newborn, and the inevitable deterioration and loss of their child. Knowledge is power and we strongly advocate for the education of diagnosis for all parents in Maryland.

Our first child, Parker Eugene was born on 11/9/2014 at Anne Arundel Medical Center in Annapolis, MD. My husband and I had already been married for four years and together for ten before welcoming our sweet, red-haired baby boy, and we were so excited to start our family. We were filled with hopes and dreams for the future and all the things' parents get to enjoy with their children as they grow.

The first few months were exhausting, and joyous. They were amazingly hard, and also the happiest days of our lives. Parker was fussy, and cried often but we were reassured that he was just fine, and this was typical behavior for a colicky baby. He had difficulties feeding and seemed to always have gas or an upset stomach, again reassured that this is also normal for a newborn with an immature GI system. He had failure to thrive/gain weight. He was diagnosed with reflux and milk intolerance and prescribed medicine and special formula. I became truly concerned right around 4 months. He would cry during feedings, he did not try to reach for his toys on his mat as he once did, he could not sit up as well, he had jitters in his right hand, he was in so much pain, and he could not sleep. I took him for his 4-month appointment and expressed all my concerns, I read them from a list. The doctor was an old, trusted friend, and he was not

worried. He reassured me that Parker was okay. I insisted on seeing a neurologist, he complied and gave me a number to call. The next day I called and was advised that the only way to get an appointment was to be the first in line on the day when you call. I called every day at 8:00am for four days in a row and never was given an appointment. A week later, my MIL was concerned he had not been eating all day. I left work and took him to the doctor and was sent to the ER with fear that he was showing symptoms of CP due to scissoring in his legs and fear of dehydration. It all happened so fast. After a CT scan, and blood work, they did not find anything to be abnormal and sent us to Children's via ambulance. We checked into the 4th floor with no trouble as a team was waiting for us. It was overwhelming to see all the staff and hearing the words metabolic tossed around. I had no clue what that meant and assumed it was a good thing, an easy fix. I remember taking a photo of the room number so I could show Parker when he was older and tell him about that crazy first time in the hospital. He would want all the details and to hear about how brave he was. My husband and I were scared, and hungry, we had no clothes or toiletries. We wanted to know what was wrong and what the plan was to get our boy to feel better. The number of doctors and nurses in and out of our room was overwhelming but assumed normal protocol.

Parker received his first MRI at Children's National on March 25th, 2015, he was 4 1/2 months old. That evening the genetics team came to tell us their initial diagnosis. They were pretty confident that Parker had Krabbe Disease. My first thoughts were "this sounds manageable," I had never heard of it so how could it be that bad? Their faces seemed so solemn, and they then shared the life expectancy which was 2 years. Little did we know we would not even get one. The next few hours were pure life shattering, heartbreaking, soul crushing devastation. We stood over Parkers crib and sobbed. On Friday March 27 the blood test confirmed that our beautiful son had Krabbe Leukodystrophy. That night I wrote this: "My baby will never grow up. He will never talk or walk. He will never play sports or ride a bike. He will never go to prom or college. My baby has Krabbe Disease. Today we found out our sweet boy has a fatal illness. Nothing can describe my pain and sorrow. I will bury my only child before his second birthday. My life, Gene's life, Parkers life have been taken from me. The prayers did not work."

We were referred to the Children's Hospital of Pittsburg to see Dr. Escolar who had performed cord blood transplants, the only treatment available for Krabbe disease, and she was the nation's leader in Krabbe research. We were discharged that Friday and headed up to PA on Sunday. We were holding on to the hope that Parker could be a candidate for transplant. After countless tests and evaluations, it was decided that Parker was not eligible for treatment, because he was already symptomatic the treatment would not be successful. He received a G-Tube to help with feeding and we were sent on our way to help our baby slowly transition into the arms of the lord in heaven.

So much love, pain and suffering occurred during diagnosis day to the day my son passed away in my arms at 10 months old on September 14, 2015. I am leaving out all the details of palliative care and prayers for a miracle. All the medications and the progressive loss of ability including swallowing, coughing, general movement. The machines needed to keep him comfortable and alive. The search for second opinions.

My ask today is that the committee take into consideration the addition of Krabbe to the NBS panel knowing there is life-saving treatment available, that the capabilities and science are already available to the state and the recent decision from the federal advisory board to add Krabbe to the RUSP. (Recommended Uniform Screening Panel)

Knowledge is power and we strongly advocate for parents in Maryland to have the education of early diagnosis.

Our families right to decide if treatment was a good fit for our son was taken from us. Our diagnosis came too late, but we believe that the right to choose treatment should be given to every family to decide on their own. We are advocating for SB117 to have a favorable outcome. The capabilities and science are already available, and treatment is proven to be successful under the right circumstances including early detection.

Thank you for your time and careful consideration.

Parker's Mama
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