

March 13, 2026

Shoemaker Family  
1811 Hatfield Rd  
Huntingtown, MD 20639

Written Testimony in Opposition to House Bill 1625  
Public Health – Newborn Screening Program – Fees and Core Conditions

Dear House and Health Committee Members,

My name is Melissa Shoemaker, and I am writing in **strong opposition to House Bill 1625**.

This issue is deeply personal for my family. My son passed away from a condition that is now included on the federal Recommended Uniform Screening Panel (RUSP) but was not screened for in Maryland until recent legislation was passed. Because of that, my family understands firsthand what is at stake when newborn screening decisions are delayed or left to discretionary processes.

Newborn screening exists for one simple reason: to save lives by identifying serious conditions before symptoms appear. The federal Recommended Uniform Screening Panel is developed through a rigorous scientific and medical review process led by experts in public health, genetics, pediatrics, and rare diseases. These recommendations are based on evidence that early detection can significantly improve outcomes for affected children.

Current law ensures that when a condition is added to the RUSP, states move toward implementation within a reasonable timeframe so that newborns benefit from advances in medicine and screening technology. **House Bill 1625 would weaken that safeguard and therefore risk lives of innocent children like my son Parker.**

By allowing the Department, after receiving recommendations from the State Advisory Council, to delay or decline implementation of new RUSP conditions, this bill creates uncertainty and potential delays in life-saving screening. It shifts Maryland away from a system guided by national scientific consensus and toward one where implementation could be postponed indefinitely.

For families like mine, time matters. Many of the conditions added to the RUSP are rapidly progressive diseases where early diagnosis is the difference between life and death, or between severe disability and meaningful treatment.

No parent should lose a child because screening was delayed, debated, or deprioritized.

Maryland has long been recognized as a leader in public health. We should continue to follow the evidence-based recommendations of the RUSP and ensure that newborns in our state receive the same opportunities for early detection and treatment as children in other states.

**House Bill 1625 risks creating barriers to that progress.**

I respectfully urge the committee to oppose House Bill 1625 and continue supporting timely implementation of federally recommended newborn screenings.

Thank you for your time and consideration and please find the testimony below about our son Parker, we shared for the support of the passed SB117 in 2024.

Respectfully,

Parker's Mama  
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### **Parker's Story**

Our family has been forever changed by the choice the state of Maryland 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.

Our family has attempted and failed on many occasions to persuade the State Advisory Council on Hereditary and Congenital Disorders 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 subject families to the very pain and suffering we should be working to prevent - the months of uncertainty when something is wrong with their newborn, the missed opportunity for early detection, and the devastating deterioration and loss that could have been avoided if newborn screening for Krabbe had remained in place is unbearable. 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 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 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 has 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 carefully consider the consequences of making it more difficult to add diseases to Maryland's newborn screening panel, especially when life-saving treatments already exist and the science and testing capabilities are available to the state. The recent federal advisory board decision to add Krabbe disease to the RUSP highlights this urgency. Policies that delay or prevent the addition of such conditions could cost precious time and ultimately precious lives for families in Maryland.

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 previously advocated for SB117 and are so thankful there was a favorable outcome, please do not let all that effort be for not. The capabilities and science are already available, and treatment has proven to be successful under the right circumstances including early detection.

Thank you for your time and careful consideration.