

To: Public Health and Welfare Committee:
From: Kim Reynolds, Heart Mom and CHD Screening Advocate
RE: SB 364
Date: February 21, 2020

On June 12, 2008 our third little girl, Breckyn, was born at Republic County Hospital in Belleville, KS. Our pregnancy and delivery were normal and uneventful. Our family of five was complete. As we settled into our hospital room, I began to notice that Breckyn's feet and hands would turn a blue/gray tint while I would hold her and/or nurse her. Upon repositioning her the color would come back for a short period of time before turning blue/gray again. I tried to not to over analyze and knew that if there was an issue her doctor would notice. Throughout the evening and next morning, the doctor and nurses came in to check on her and no one made mention to the off color of her extremities. We were released that afternoon and began to settle into our new routine. Over the next week, I began to see signs in Breckyn that something was not quite right. I would have to wake her up to feed her and she would only be able to nurse a couple minutes until she was exhausted and fall back to sleep. I took her back for her check-up and she had lost weight. The doctor had no concern and told me to drink Ensure to make my milk richer. I took her back in the next week for a weight check and she had lost a few more ounces. I shared my concerns about her not being able to stay awake during feeds and having a hard time stimulating her throughout the day. The doctor suggested I start supplementing her feedings with formula. This charade went on for six weeks with noticeable changes in Breckyn's appearance such as cyanotic coloring and labored breathing and she had developed a cough. Not one time was she ever monitored through a pulse oximetry screening or did the doctor listen to her heart. Through a turn of events, we ended up in the emergency room in Belleville the evening of July 21st where we quickly learned Breckyn's heart was enlarged and her oxygen saturation levels were 60%. This emergency room visit was the first time she had been hooked up to a pulse oximetry machine. Her organs were shutting down.

Breckyn and I were flown to Children's Mercy Hospital in Kansas City where the doctors worked hard to stabilize her. Within an hour or so after arriving my husband and I were given the diagnosis. Breckyn had three congenital heart defects; Transposition of the Great Arteries, Pulmonary Stenosis and a Ventricle Septal Defect. They needed to rush her into an emergency heart catheterization for an Atrial Septectomy. All of these words were as new to us that evening as they may be to you today. Imagine having your world flip upside down and trying to have all of this explained to you. After the procedure, Breckyn was stabilized and we spent the next 7 working with the cardiologist trying to develop a plan to mend her heart. What we learned during those days was devastating. In visiting with our cardiology team, we learned that if Breckyn was given the pulse oximetry screening at birth, her heart defects would have been caught, she would have been immediately referred on, a surgeon could have performed the Atrial Switch surgery and she would be repaired. However, because she went undiagnosed for 6 weeks, she developed the pulmonary stenosis which makes it impossible to do the atrial switch surgery and were only given one other choice for surgery. On day 7, Breckyn's body was still unable to compensate for her damaged heart and she was rushed back for an emergency open heart surgery where they once again tried to alleviate the some of the work her heart was trying to do. Twenty-one days late we were dismissed.

Through the next two years of our new "normal" life, we were confined to the house. Breckyn's immune system was comprised and the doctors feared that if she got sick, her heart would be unable to recover. During this time, Breckyn averaged an open-heart surgery every nine months due to the artificial pieces of her heart not being able to sustain the high blood pressure in her heart and lungs. During this time, Breckyn was diagnosed with Pulmonary Hypertension. The Pulmonary Hypertension was once again the result of her heart defects not being diagnosed at birth. Because of the Transposition of the Arteries,

blood was being pumped at higher volumes through the aorta to the lungs. The lungs began to drown. The body compensated by over producing endothelial cells to line the inside of the vessels making the entry into the vessels smaller and taking away the elasticity. Pulmonary Hypertension is terminal, there is no cure. Once the damage to the lungs is done, it is irreversible. Doctors work tirelessly to try to keep Breckyn's pressures in her heart and lungs tolerable and stable in hopes that a cure will be found.

Breckyn's journey has been hard. After the first three open heart surgeries at Children's Mercy in Kansas City, we had to get a second opinion which led us to Boston Children's Hospital in Boston Massachusetts. Today, Breckyn is 11 years old. For nine years we have been traveling to Boston every six months for complete check-ups. Five open heart surgeries, 16 heart catheterizations, two valve replacements, numerous hospitalizations due to not being able to fight off common colds, flu, pneumonia and more, we continue to fight for her health.

In 2014 and 2015, I worked with another heart mom, Traci Poore and lobbyist Kevin Barone to try to bring light to the importance of requiring Pulse Oximetry testing on the newborn screening. I visited with numerous Legislatures only to be told that "they don't like to tell doctors what to do." One of the conversations that continues to stick with me was after telling my story to Rep. Barbara Bollier. In the conversation I let her know that we are up to total cost of about \$2M. She asked me if we had private insurance or state insurance. I told her we had private insurance. She told me she was glad to hear that because our issue would be costing the state insurance too much money and it didn't have that kind of funding. I was literally speechless.

I was appointed as a parent representative to the KDHE's newborn screening task force along with Dr. Gertz from KU Med and Dr. Kaine from Children's Mercy. At that time, it was suggested for the KDHE to put together a training program to go out and train rural hospital personnel on how to utilize the pulse oximetry test to screen for congenital heart defects. I voiced my opinion on how it was a waste of KDHE funds since all nurses and doctors are trained to administer the test already. Not only is it given every time you enter a doctor's office for a check up but at the time, I worked at a community college with a nursing program. Every year I was asked to come and present our story. Every one of those nurses going through the LPN or RN program confirmed to me they were highly trained on pulse oximetry screening. This marketing and "training" program were deployed throughout the state with thousands of dollars spent.

The two most important things to remember when considering this bill in regards to congenital heart defect screening is this:

1. The American Pediatric Association requires all pediatricians to administer the pulse oximetry screening test to all newborns prior to dismissing them to go home. Therefore, in areas where pediatricians practice (metro areas) these defects are caught, babies are referred on and the condition is diagnosed and proper procedures are immediately put into place to correct the defects and save the babies lives. Therefore, mortality rates of babies born in hospitals where pediatricians practice is lower.
2. In rural Kansas, we do not have the opportunity of birthing at hospitals with pediatricians on staff. Our babies are delivered by Family Practice doctors. Family Practice doctors may be setting a broken bone, diagnosing strep throat, removing a gall bladder and delivery a baby all in the same day. They have to know a little about a lot of different medical ailments. They are not a specialist in all areas. And, Family Practice doctors are NOT required to complete a pulse oximetry screening on babies prior to dismissal.

As Dr. Kaine explained to our group, when a baby is dismissed from the hospital undiagnosed and goes home, the condition of the baby deteriorates. IF that baby makes it back to a hospital, they are then transported to the nearest hospital that can help them. By the time that baby gets to a hospital like Children's Mercy, their condition is so dire that it is much harder to save their life. Therefore, the mortality rates are higher. If they are blessed as in our case, they fight a life long battle.

As in Breckyn's case, her physical activity is limited. She will never play a sport, run a race or do normal activities. She will always have a compromised immune system and has to be extra careful during cold and flu season. This week alone she has missed the entire week of school because Influenza running through our school system. It is too risky to allow her to be exposed.

When you look at the battery of newborn screening tests, how many of those tests are test that are NOT life threatening? Those tests have been mandatory for years, but we do not mandate critical congenital heart defect testing. How about testing for Maple Urine syndrome. I have asked doctors what Maple Urine Syndrome is and have yet to get an accurate answer. However, we will not mandate a \$4 test that takes less than two minutes to administer and can save over 4, 000 babies alone in the state of Kansas per year.

There is so much more to Breckyn's story. Above is just the highlights. But if I can leave you today with one thought, what if this was your child or grandchild. What if you witnessed child/grandchild coding in front of you with doctors doing chest compressions and trying everything to save your child. What if you knew that all of this could have been avoided with a \$4 test? Would the mandating of this test be important now?

Breckyn has a life-long terminal condition because pulse oximetry screening was not mandatory. Her condition will kill her. Our family lives with that every single day. My mission has always been to bring awareness to the important of pulse oximetry screening. I vowed when Breckyn was 6-weeks old lying in a hospital bed, that this mommy would do everything she could to make sure another baby and another family would never have to go through what she was going to have to go through. How many more families have to suffer?