Testimony on House Bill 2250
Social Services Budget Committee
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Newborn Screening Advisory Board Member

My name is Karey Padding and I am here today to ask you to support HB 2250 because all babies born in the great state of Kansas deserve a healthy start. Newborn screening is truly one of the 20th century's great public health success stories. It should not matter where you live, all babies should be screened at birth. Newborn screening saves lives and can drastically change the trajectory of life for babies and their families.

An efficient and effective newborn screening program is important to me because I became a mother for the first time on a warm November day in 2010. A quick and simple test approximately 24 hours after Gavin James was born, the newborn screen consisting of a small heel stick and blood spot test, would make a big difference for us in the weeks and months to come. A few days after we arrived home from the hospital, we received a call from our pediatrician's office asking us to bring Gavin back in because one of his tests came back abnormal. We were scared and a bit sleep-deprived, but of course, we complied, and the blood spot test was re-done. A few days later, we received the call from our pediatrician, confirming the abnormal screen for cystic fibrosis. We were shocked, devastated, scared and had so many questions. "What does this mean for Gavin? What do we do next?" We were quickly set up with an appointment at the CF Clinic in Wichita to have Gavin undergo a sweat chloride test, which ultimately confirmed his diagnosis. After the first care center visit, Gavin began a daily regimen of enzymes, inhalers, nebulizers and CPT (chest physical therapy). A daily regimen he continues to this day. I couldn't believe my three-week old baby was eating applesauce off of a spoon and taking enzymes with every meal – he wasn't even holding his head up yet!

It took many months to reflect back on our birth and diagnosis story to realize how truly lucky we were that Gavin's first few weeks of life set the course for the best possible health outcomes and it all started with the newborn screen identifying his cystic fibrosis. I have several CF mom friends who have older children that were not screened in Kansas or not screened for CF initially who's babies struggled with their weight, health and endured numerous medical appointments and

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hospitalizations before the real cause of their failure to thrive was finally identified as cystic fibrosis. It caused significant financial strain for families as well as taking a toll on their emotional, mental and physical health.

I am so thankful for the Newborn Screen and the early detection of Gavin's cystic fibrosis. I believe he continues to grow today because preventative treatments were started prior to symptoms. We are also grateful for the incredible support from the Ascension Via Christi Cystic Fibrosis Clinic staff, Mid-Kansas Pediatrics and the Cystic Fibrosis Foundation, who have been on this journey with us since the beginning.

HB 2250 allows for all newborn Kansans to continue having the advantage of early diagnosis of metabolic and genetic diseases which greatly benefit from early treatments and interventions. Please consider increasing the capitation to expand this life-saving and life-changing program to continue to meet the needs of the many families served through this screening program. Our story, Gavin's story is a personal success story and a public health success story. Gavin is growing, thriving, and healthy because of an early diagnosis and treatment, and it all began with a few drops of blood and a hearing test to set my baby on a healthy path.

I urge you to support House Bill 2250 and I thank you for allowing me to share my story with you today.

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