

Thank you for the opportunity to speak on behalf of HB 1081 and to tell you my story.

My name is Lesa Brackbill and I live in Hershey with my husband, Brennan. We have a personal connection to this bill and to Act 148 of 2014 and I'd like to briefly share that with you.

Our daughter, Victoria, was born on July 30, 2014 at Harrisburg Hospital and she was perfect. She was healthy and smart and met all milestones until five months of age; all of a sudden, she became increasingly irritable, stopped eating, lost weight, and no longer smiled, laughed or played.

Six weeks after symptoms began, and just two weeks after we took her to Penn State Hershey Medical Center for a CT Scan, the doctors at Hershey diagnosed our baby girl with Krabbe Leukodystrophy and told us that it was terminal. On February 13, 2015 our lives changed forever.

To make matters worse, they informed us that because it was genetic we shouldn't try to have more children. Tori was the third child in three years to be diagnosed with Krabbe at Hershey Medical Center, and we are so thankful that they are currently the only hospital in the entire state screening each and every baby for Krabbe automatically.

We were told that there was nothing they could do to treat the disease and that she would pass away before age two. And they were right - there was nothing we could have done **at that point**.

However, we quickly learned that if they had screened Tori at birth for Krabbe they could have treated it, and that the treatment - though complicated - has a high success rate. I'm not sure which news was worse - that our daughter was dying or that they could have done something about it six months earlier.

We then learned that in October 2014 a bill had been signed into law making Krabbe one of the mandatory Newborn Screenings, but that it hadn't been implemented yet. And so our journey began of doing everything we could to help Hannah's Law be used as it was intended.

I have attended the meetings of the Newborn Screening Advisory Panel for the last year and have been encouraged by the progress that has been made in educating the panel about the treatment for Krabbe and its effectiveness. Though the Panel did not see things our way initially, we're all basically on the same page now, and for that Brennan and I are grateful.

Through these meetings I have learned a great deal about Pennsylvania's Newborn Screening program and I still cannot believe that we are nearly last in the nation for the number of mandatory tests that are done per child. You are likely aware of this, but each hospital in Pennsylvania chooses which diseases for which they will screen because currently they absorb the cost for all but the "mandatory" panel of 9 diseases. The remaining 27 on the supplemental panel are not mandatory. This means that in this state, your ZIP code determines your life or

death if you are born with a disease like Krabbe. This simply isn't right. This bill would change that by merging the two panels so that all diseases are equally screened and every baby has a chance at life.

However, there's a significant hurdle which holds back Hannah's Law and endangers the lives of children every day: money. There's not enough money, we're told. This bill would change that as well. By changing to a fee-based system - as most states already use - the state would have the necessary funds to ensure that all babies are screened equally and for as many diseases as possible.

Money shouldn't be the determining factor in doing everything we can to save the lives of babies who are born with genetic diseases. Whether it would be paid by the parents or by insurance - and insurance currently pays for much more frivolous things during the labor and delivery process - it is a much-needed change.

As a parent, I'd rather pay for Newborn Screening than for a funeral, and that's what we had to do. Our daughter passed away last year, on March 27, 2016, at twenty-months of age. She never walked or talked, she never smiled again, and she was robbed of the opportunity to live a full life all because Krabbe wasn't caught quickly enough. And we as parents were robbed of the opportunity to do everything we could to save our daughter's life.

Making HB1081 law will help ensure that babies are given the best possible chance of life no matter which of the 36 diseases on the Pennsylvania panels are in their DNA. It was too late for Tori, but it doesn't have to be too late for other Pennsylvania babies who will be born with this - or one of the other 35 - horrific diseases.

Thank you in advance for making a difference in the lives of families in Pennsylvania.