

Anna Newell – Testimony

January 20, 2016

My husband and I lost our first son in August of 2012 when he was stillborn at 29 weeks gestation. Up until he died, I had a normal, low risk pregnancy. I was in my late 20s, healthy, a non smoker, married, I have a bachelor's degree – I was the definition of low risk.

One day I noticed that the baby hadn't moved – no kicks or punches. I brushed it off and thought I had just been too busy to notice. The next day he still hadn't moved. When I went in to the doctor for a sonogram, they confirmed what hadn't even occurred to me. Our baby wasn't alive. What followed was the most traumatic, life changing experience of my life. My labor was induced and the next day I delivered a beautiful baby boy, still warm with chubby cheeks. We named him Cash and we spent the next 20 minutes holding him trying to memorize his features.

We decided to have an autopsy done and any and all tests that could be done on my husband and I to figure out what happened. The cause of death could not be determined.

I spent the next year researching stillbirth. I learned that about 50% of stillbirth deaths are for unknown causes, like ours, even after autopsies are complete according to March of Dimes. The stillbirth rate in the United States is 1 in 160 pregnancies according to the American Congress of Obstetricians and Gynecologists. And yet it didn't even cross my mind that my baby could die, even after he stopped moving. I thought stillbirth was a problem of the past and that with my fantastic doctor and today's medicine, stillbirth was an impossibility. As HB2324 states "although studies have identified many factors that may cause stillbirths, researchers still do not know the causes of a majority of stillbirths." I decided something had to be done. When families are losing babies and half of the time no one knows why, there is not enough research being done.

Our legislation, HB2324, has two basic parts; the dignity section on policies and procedures outlined for hospitals and birthing centers on treating families going through a stillbirth and the research and data collection portion that strives to reduce the occurrence of stillbirth.

Section 4 outlines policies and procedures for hospitals and birthing centers. After introducing this legislation last session, I have had the opportunity to talk with many key stakeholders. I understand how this section may be burdensome and may overlap policies that are already in place at hospitals around Kansas. To ensure all hospitals are up to date on treating stillbirth families, we have discussed providing education and training to hospitals around the state outside of our legislation. I am willing to support removing this section from the legislation and focusing solely on the research and data collection portion. However, I would like to recommend retaining paragraph 9 under Section 4 and add "*This would include encouraging physician communication with the family regarding the importance of an autopsy, the significance of autopsy findings on future pregnancies and the significance that data may have for other families.*"

Sections 5, 6 and 7 outline the data collection and evaluation portion of the legislation. By first defining fetal death evaluation protocol for data to be collected, requiring the establishment of a database to record all data collected and requiring evaluation of that data for purposes of identifying the causes of, and ways to prevent, stillbirths. Section 7 states that the department may contract with a third party including a public institution of higher education in the state. I have met with The University of Kansas Medical Center's Dr. Catherine Satterwhite in the Department of Preventive Medicine and Public Health. She is excited and willing to take on this portion of the legislation. She has provided an estimate that outlines costs associated with the design, data collection, database creation, maintenance and reporting as outlined in our legislation. Line 12 of page 4 would need to be amended "in the state or a foundation, *for any or all portions of the data collection/evaluation.*"

After losing Cash, we went on to have two very healthy pregnancies and have two wonderful sons at home. I am standing here today because I want to do my part in trying to reduce the occurrence of stillbirth so my sons and families around Kansas will never have to experience the trauma of losing a child before they even get to meet them.