

Thank- you for allowing me to present to this committee: Health and Human Services, regarding House Bill No. 2324- Newell Stillbirth Research and Dignity Act. My name is Dr. Libby Rosen, I am an RN, Professor of Nursing of Childbearing Families at Baker University, Stormont Vail Health Campus. I have been a labor nurse for 42 years and I speak about this bill from a personal perspective representing myself, my experiences as nurse and my understanding of obstetrics as a PhD researcher. My husband Eric and I experienced the death of our daughter Laura through stillbirth in October of 1980. Since that time I have spoken locally, regionally, nationally and internationally on the subject of pregnancy and infant loss and began the Pregnancy and Infant Loss Support Group in Topeka in 1990. This bill could help us to find some ways to reduce the incidence of stillbirth- something that has not happened in all the years that I have been practicing. At the time of our loss there were no programs available to address grieving expectant and new families and little education for the health care professionals. Over the last 35 years we have come a long way in our approach and sensitivity to grieving families but still have strides to make.

After Laura was stillborn we were offered an autopsy. The only mothering I thought I could do for her was to protect her and the idea of someone doing an autopsy on her was too much to consider. It appeared evident that she died from a knot in her umbilical cord that had been pulled tight. Yet 3-4 months later, during the grieving process, I was in the yearning and searching phase according to grief experts Bowlby and Parks, and I wondered what else might have been wrong, what if there

was a heart defect or something that would happen again with the next pregnancy. When I tell my story I share that our decision to avoid the autopsy was one of the regrets that I had. I can say that many of the couples I have had the privilege to serve have also struggled with wondering later about what might have been wrong or what had happened to their baby and wished they had been given more information about autopsy options. As a member of a Fetal Infant Mortality Review Board in my county- we need facts and stats to make any suggestions about how we can lower the elevated fetal and infant mortality rates in Kansas, which are higher than the national average. I fully support the adoption of Sections 5,6, and 7 of the bill.

While I fully support the research component of this bill that will help in this goal of stillbirth reduction, I am reluctant to support the regulation of policies and procedures for hospitals. I have worked in nursing management and as a staff nurse. Policies and procedures are best tailored to the hospital, their health care team, and individual families- not mandated by the legislature. Guidelines are good and could be described along with sample policies and procedures that each hospital could adopt to their environment. Everything that was in the bill is absolutely appropriate for care, but could be accomplished with educational initiatives.

I have spoken with the Kansas Hospital Association staff about the possibility of making such an initiative part of the Kansas Hospital Association programs through webinars and hospital education. They were very open to this and stated that they

will work with us on such an initiative. We have been very successful with the KHA and the United Methodist Health Ministry Fund implementing the High 5 for Mom and Baby Program in which Gwen Whittit and I will have provided education to 58 of the 69 delivering hospitals in Kansas during the last three years about the importance of hospital care for breastfeeding mothers, impacting 94% of the babies born in Kansas. Just as we have with that initiative, we can make a difference in the lives of grieving families through education and support of hospitals that provide the care for families grieving the stillbirth of their baby. We can teach about the Count the Kicks program for prevention as well as appropriate hospital care for families in the devastation of lost dreams and hopes for their baby following his or her passing.

Thank-you for letting me share with you my support for the research component of this bill. And to Anna Newell for her dedication to bring this important topic to the forefront and minds of those who can help make a difference.