House Federal and State Affairs Committee
Kansas Senate Judiciary Committee

9:00 AM, Room 346-S
Testimony Opposing HCR 5019
Phil Wood
Tuesday, January 21, 2020

Dear Chairman Barker, Chairman Wilborn and Members of the Committees,

Thank you for the opportunity to express my deep opposition to HCR 5019.

I have decided to speak to your committee today in hope that some of the experiences of my family would be informative to you as you consider the issue of late term abortion. My wife and I were faced with the difficult experience of having to abort our much-wanted twin sons at 22 weeks' gestation. I believe you will agree with me when I say that we did everything we could to carry this pregnancy forward but had to make this difficult choice on the best medical advice we had available. While I can claim to special insights into the very complicated issue which faces the committee by virtue of these experiences, I believe that our experiences may help shed light on the complex medical and personal issues involved in the termination of such pregnancies. Our experience especially highlights many considerations involved in determining risk to the health of the mother. To summarize major points, I wish to emphasize in my reading of the proposed legislation, I would like to note:

A. That there is a difference between a fetus which is "nonviable" and one which is "dying." I am particularly disturbed by the language in the committee which defines viability as a "stage" implying that viability is a sole function of gestational age.
B. That the children involved in our last pregnancy were genetically healthy, but, nonetheless "nonviable."
C. The language of the proposed legislation does not consider the case of multiple fetuses and, in our case, the best medical advice prior to our abortion was to terminate one fetus in an attempt to save the other.
D. That in some cases a pregnancy can cause a health risk to the mother which may prevent the possibility of future pregnancies. Further, decisions regarding whether to continue a pregnancy and the evaluation of the risk to the mother are complex. Our experiences provided us with no "clear bright line" test which may be applied across all pregnancies. Our decision was made on the best medical information we had from the several doctors we consulted during this time and, more importantly, changed in dramatic ways over the course of the pregnancy.
E. In many ways my family was "lucky" in that we were able to save up enough money to end this pregnancy in a way which did everything we could to preserve the health of my

wife. Had we not made it a regular practice to save a substantial portion of my paycheck, or if I had made less money than I do, our situation would have been much more difficult.

That many of the hardships which we encountered were due to the fact that no medical facilities were available in the State of Missouri to perform the abortion which was necessary.

A short personal description.

Before describing our experiences, it is perhaps helpful to tell you a bit about myself. I teach at the University of Missouri in the Psychology Department. My wife and I both are active in our community and church, St. Andrew's Lutheran Church in Columbia. My wife and I are fortunate in having an adorable daughter, Julie, who is now a graduate student in Pennsylvania State University and a son, Justin, age 20, who we adopted from China. I could be like any of your neighbors or constituents.

Our Pregnancy

Let me begin by first telling you that this pregnancy was very, very much wanted. Three years earlier, my wife had an ectopic pregnancy. Although we do not know if the ectopic pregnancy was to blame, we were not successful in our attempts to become pregnant again after that. After that, we began to work with a fertility clinic. We decided to have a GIFT procedure done, a surgical procedure which involved harvesting eggs from my wife, mixing them with my sperm, and returning them to her fallopian tubes. It is worthwhile to note that our use of the fertility clinic was in no way related to the medical difficulties which followed.

My wife and I were overjoyed to learn that this last procedure had been successful and that she was now pregnant. We soon learned that she was pregnant with twins. Our twins were, however, diagnosed as having two amnions, but a shared placenta. We did not discover the implications of this facet of the pregnancy until the 16th week of her pregnancy.

Identical Twins

Identical twins are quite rare, relative to fraternal twins. It is estimated by the Twin-Twin Transfusion Syndrome Foundation (http://www.ttsfoundation.org/index.html) that up to about 15% of all identical twin pregnancies involve some degree of twin-twin transfusion syndrome if two amnions and one placenta are present. In twin-twin transfusion syndrome of the blood vessels of the fetus fails to return to it and instead crosses over to the circulatory system of the other twin. This transfusion poses great problems for both twins: The donor twin does not get all of the nourishment it needs because it doesn't have enough blood. The recipient twin suffers as well, because fetal blood is thick and pumping it places a burden on the heart of the fetus, causing the walls of the heart to thicken. It is difficult to know how many identical twins actually have this, given that such transfusion goes undiagnosed. I hasten to add that the twins involved

are genetically and, apart from the difficulties posed by the transfusion "healthy." Twin-Twin transfusion syndrome is a disease of the placenta.

The Problems

We first because aware of the problems with my wife's condition at 16 weeks, when we went to have an amniocentesis. Twin-Twin transfusion syndrome was diagnosed. The degree of transfusion was pronounced: One twin being a "stuck twin" meaning that it had little or no amniotic fluid around it, while the other twin had a surplus of fluid. We learned at this time that this condition is a disease of the placenta and that this condition put one or both of our twins at significant risk for cerebral palsy, mental retardation, and/or serious heart problems. The "donor" twin, who is giving blood to the other, can have stunted development while the recipient twin, who received the blood from the other, can have heart strain due to the effort of pumping the thick neonatal blood from his twin.

What follows is an annotated chronology of what happened next, which I've reconstructed from medical records and our best recollection. I apologize that some of the medical details are rather graphic, but I believe you need to know what we knew and when we knew it, and how the available medical details we had informed our private health care decisions at the time. I believe you will also understand that we did not choose to terminate this pregnancy at the first hint of potential problems.

Week of Gestation	Event
16	Twin-Twin Transfusion diagnosed. Serial amniodrainage was done. This involved taking a large needle and draining about a liter of amniotic fluid off. It was hoped that resolving this fluid imbalance would help the transfusion syndrome to spontaneously resolve.
17	We learned the donor twin was diagnosed with club foot- presumable due to the fact that he had little or no amniotic fluid. It appeared that fluid had not re-accumulated around the larger twin. a physician we consulted with advised an additional ultrasound with high resolution in order to determine if there were additional problems with the twins.
18	Standard ultrasound revealed that the second twin had two club feet.
19	High resolution ultrasound reveals that, in addition, the transfusion problem appears to have interfered with the generation of kidneys in the smaller twin (although this is not certain at this point). This baby has no kidneys, no renal artery, and no bladder. In addition, the amniodrainage which was done has resulted in free-floating amniotic bands between the twins. These bands, which can wrap around the head, fingers, arms, feet and hands of the fetus, can result in amputations. In addition, these bands, if swallowed, can result in cleft palate and/or throat. Banding is described as "severe." My wife is now on bedrest. I care for my wife and daughter as best I can and juggle my work week accordingly. Doctors conclude that one twin poses a present clear risk to the life of the other and recommend a

	procedure in which the umbilical cord of one twin is tied off, causing it to die, and thereby prevent excess blood going to the other twin. Such surgery is unavailable in Columbia, and we are referred to a specialist in Florida for the procedure.
20	Amniotic fluid is increasing in my wife, but no further drainages can be done because these bands float toward the needle and prevent the withdrawal of further fluid. My wife now looks as if she is nine months pregnant.
21	It is not possible to fly to Florida- no airline will fly a high risk pregnancy. I borrow my parent's van and we drive to Tampa, with my wife in the back of the van on a cot. It takes us two and a half days. My wife is very uncomfortable. The doctor in Florida informs us based on his ultrasound that surgery is impossible because the larger twin is now in heart failure, the amniotic banding is too severe, and his instruments need intact membranes to push against in order to do the surgery. He tells us that both twins will die, with or without surgery. He tells us that we should get an abortion if we ever plan to have another pregnancy, because of the risk of rupture to the uterus. There is some risk of amniotic embolism for my wife as well. His hospital, a Catholic institution, cannot perform such a procedure and he tells us to go home and find an abortion clinic. No doctors at this hospital or in Missouri told us that the pregnancy posed a risk to my wife's life, I would like to point out. I drive back to Missouri with my wife in the back of the van on the cot.
22	We attempt to get an abortion in St. Louis. They refuse to do this after evaluation because they say that the head of the larger twin is too large. The give us a sheet of paper with the addresses of three clinics- one in Atlanta, one in Houston, and one in Wichita. After consulting with our physicians, we choose Wichita. We set up an appointment at the clinic at the next available time, which is three days later.

I hope that the above chronology gives you a flavor of the many changing considerations which faced us during this time.

The Abortions.

I probably do not need to tell you all the details concerning our visit to the clinic. I would like to give a general flavor, though, in mentioning the abortion protesters, their uninformed, but impassioned emotional harassment outside the clinic, especially at the sight of my wife, which appeared to outward appearances as if she was nine months pregnant due to fluid buildup. Inside, the laws of the state of Kansas require us to fill out forms describing the developmental progression of our boys, focusing on their ability to feel pain, how human they look, and basic descriptions of brain development. Although I feel the document was clearly designed to put more of an emotional burden on us, I found myself wondering what quality of life my boys would have if we continued the pregnancy further. "Surely they cannot feel very good in utero being as sick as they are," I thought.

The doctor, George Tiller, was especially caring and helped us to go through this ordeal together. (This was obviously prior to Dr. Tiller's murder while serving as an usher in Reformation Lutheran church for performing abortions such as the one I describe.) I was also present when the lifeless bodies of my sons were delivered. The doctor took care to allow both of us to see our boys, and I participated in a baptism for them which, while very sad, meant very much to me. I was gratified when, weeks later, a package arrived in the mail containing photographs of our boys which someone at the clinic had taken.

My observations and conclusions

- Late term abortions are not as available as the general public believes.

At the clinic we met and got to know other couples who were going through similar problems from New York City, Chicago, and Texas. Although they didn't have twins, they all had similar cases where a genetically healthy child had something bad happen in utero (e.g., a disruption of the food supply to the fetus, viral infections in the uterus, heart failure).

- What if we had waited or if the situation had become even more serious?

I have no idea, of course, what medical course would have been indicated if my wife had presented to the clinic in great distress with little time to preserve her health. I assume that such is the situation which calls for the partial birth procedures which your committee is considering. In such situations, there is often no clear bright line which details exactly when the life and not only the health of the mother is at risk. If such would have been the case for us, I feel I can speak for both my wife and myself in saying we would not hesitate to have such as procedure done on her in those circumstances.

I do not know if my daughter and son would have a mother if we had not had this procedure or, if she did, what our lives would now be like. I shudder to think what would have happened to us if we had not saved the resources necessary to pay for the medical care we required. Individuals without such means are in dire straits indeed.

- Was our experience typical?

You may think that the situation I describe must be quite rare. I cannot present, by virtue of experiencing our loss, that I can know anything about the incidence rates of other problems. As a scientist, I can only suggest that carefully controlled information be gathered if you feel it necessary to know this. Our experiences, however, represent the issues which parents face when the unexpected happens and the only ones genuinely qualified to make these health care decisions are our physicians and ourselves.

- A final note of thanks.

I have much gratitude to the physicians who helped us during this time. I would like to argue that the most competent and intelligent decisions regarding the care of my wife and the children from this last pregnancy were made in consultation with the physicians who helped care for us. To our surprise, many of the physicians had not even heard of the conditions I have described. The experience of this pregnancy, which began with such promise was, I believe, at times difficult for the physicians who cared for us as well. Sometimes, however, the right decision is one which involves great difficulty.