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CAPITOL UPDATE

Capitol Update: Rep. Lusk highlights testimony from OB/GYNs on Value Them Both amendment

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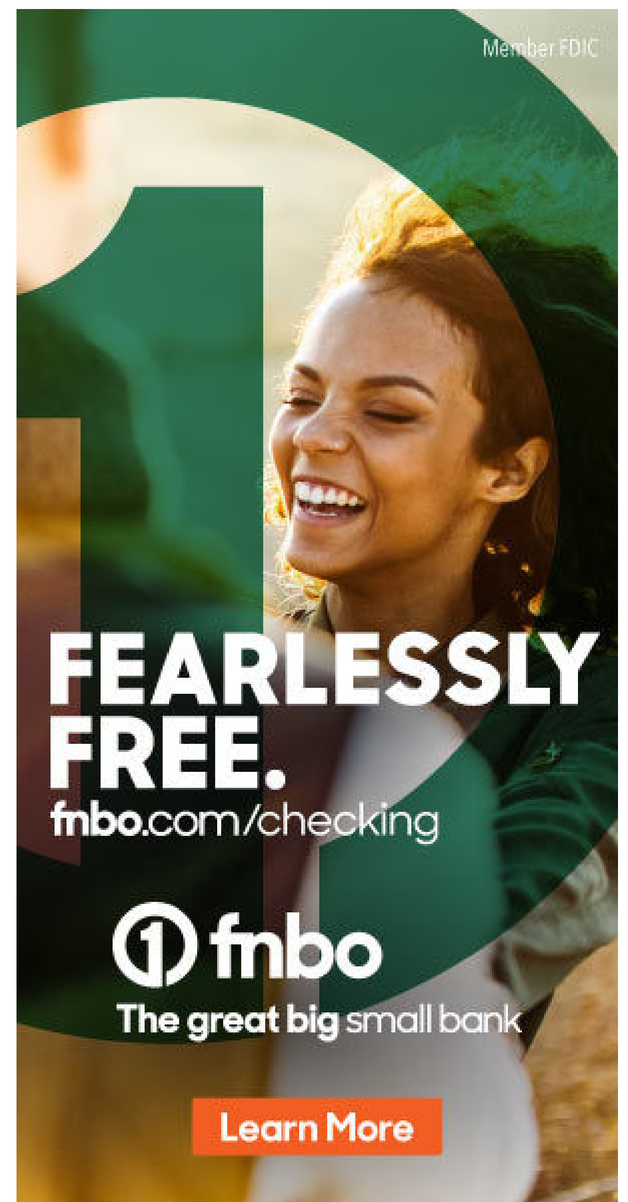
Rep. Nancy Lusk.



Each legislative session, we provide Shawnee Mission area legislators the opportunity to share their thoughts about what's happening in the state capitol. Rep. Charlotte Esau, Rep. Nancy Lusk and Sen. Pat Pettey are scheduled to send updates this week. Rep. Lusk's column is below.

There is an aspect of the abortion debate that did not get discussed in House floor deliberation on Feb. 6 to amend our state constitution, which was a shame because I think it is the most compelling. The amendment proposal would deny all rights to an abortion with no exceptions for any emergency medical complications that would put the pregnant mother's life or health at high risk, or because the fetus has a severe condition which is certain to result in death either before or after birth.

What was missing from the debate was an understanding of the real-life tragic circumstances that can necessitate an abortion. Fortunately, eight obstetrician-gynecologists submitted testimony in opposition to the amendment for the January 21st committee hearing, and in doing so they

put a human face on such situations. I would like to share the following excerpts from their testimonies. (They changed names to protect patient confidentiality).

Tara Chettiar, MD: Last year I faced the heartbreaking task of calling a patient to tell her that the baby she and her husband were so excitedly expecting had a fatal genetic disorder and would not survive after birth. She was devastated and we cried together. Then we were able to discuss options, and, in the end, she exercised her right to choose how she could best care for herself and her pregnancy. She elected to terminate. She is happily now expecting again and so far, the pregnancy has been uncomplicated.

This is by no means an anomaly, every OB/GYN you talk to can tell you stories about how abortion has been a therapeutic medical intervention for a patient. We have faced situations where legal restrictions to terminating pregnancy has put a mother's life at risk. We had a patient at a local hospital recently who unfortunately, was diagnosed with the early rupture of her amniotic sac. Meaning her water had broken before she was even half-way through her pregnancy. She began to develop an infection. She had children at home. The expertise of every doctor consulted was that the likelihood of this baby to survive was zero and the longer she stayed pregnant the more likely she was to die of this spreading infection. Instead of the doctors and the patient deciding what was the safest for her, they were calling lawyers to find out if they were breaking the law by trying to save her life.

The reality is that abortion is a necessary medical procedure for these women and others…The decision on when, how and for whom an abortion can be provided should be made in the exam room, not on the legislative floor.

Emily Boevers, MD: As an OB/GYN, I see patients who have terrible and unexpected pregnancy findings including genetic abnormalities and fetal malformations that are incompatible with survival. While these babies would not survive for long after birth, the emotional trauma of delivery and watching a child die is worse for some patients than the choice to end the pregnancy. I recently saw a patient in clinic who discovered that after two miscarriages and years of trying to achieve pregnancy her baby had a terrible genetic condition and would likely die during delivery or shortly after. The moments spent in the clinic comforting this patient were excruciating for me and devastating for her and her spouse. After so much loss, they had the option to either let their baby go now without the process of delivery or let her baby go later after a labor and delivery. There was no good choice but, importantly, she had a choice. When people are going through so much already, I feel it is important to be able to offer them some autonomy to make the decision that is best for them and their future health.

Valerie French, MD, MAS: I cared for a woman a few months ago, I'll call her Susanna. Susanna and her husband were delighted to discover their first pregnancy, which passed without complications. She delivered

a baby girl, bringing joy to their family. But their baby girl got very sick very fast and ultimately died at nine days old. Susanna explained that she and her husband were carriers of a rare genetic condition called autosomal recessive polycystic kidney disease. They had a 1 in 4 chance of having a baby with the disease, which is often fatal. Susanna and her husband grieved the loss of their baby.

With modern medicine, they were able to learn early in their next pregnancy that their son was not affected by the disease. They delighted in having a child and wanted to give their son a sibling. But early genetic testing found that that Susanna's third pregnancy was also affected by the condition. After reviewing her diagnosis, Susanna and her husband decided to end the pregnancy. The did not feel that they could endure the pain that they had experienced with their first pregnancy.

I have shared great joy and great pain with patients as they navigate a pregnancy. The complexity of the decision families face when hearing a devastating diagnosis and difficult prognosis cannot be understood by a legislative committee. Even if you heard the stories of hundreds of families that have faced this decision, you would only be at the very tip of the iceberg.

This decision is an intricate balance of medical risk, personal spirituality, and family values among so many other things. Women who have a pregnancy complicated by fetal abnormalities, like my patient, are thinking of the suffering that their baby would endure if they delivered. They choose abortion out of compassion…If I have learned one thing from the many journeys I have taken with patients in their pregnancies, it is that you cannot understand a situation until it happens to you. I have learned that women can and must be trusted to make the best decisions for themselves and their families. I stand with my patients. I support continued access to safe, legal and accessible abortion.

Stephanie Amaya, MD: Pregnancy, unfortunately, is not a simple process, and pregnancy does not only occur in young healthy women. In fact, I view my practice as a physician as a calling to serve those that are vulnerable and sick . . .

Mary is 34 years old; she works at her family's antique store and takes care of her two young children. She had dissuaded her husband from taking her to the hospital for a few days while she was feeling sick with fever, chills, and back pain hoping that it would quickly resolve. But it did not. Eventually, when he brought her to the hospital she was diagnosed with acute leukemia, a type of blood cancer that is quick and deadly. On the day Mary found out she had an aggressive cancer requiring immediate treatment, she also found out she was pregnant. She was in the first trimester of pregnancy in which the necessary chemotherapy to save her life posed a serious risk to the developing early pregnancy. To make matters even more complicated, due to her body's natural defenses no longer working, she also had a large bacterial growth on her spine that threatened her ability to walk in the future if not immediately surgically treated. Mary was distraught from the cancer

diagnosis and absolutely overwhelmed with the consideration of pregnancy when she was just told she had to fight for her own life. At this point, she told me it was not just about her life, but her life that she dedicated to seeing her children grow up . . .

It is a situation like this that highlights the extreme complexity behind each individual patient experience. The decision to have an abortion is a decision that no one except for a patient, her family, and her doctor can make. Any discussion outside of the medical practice regarding abortion is incomplete and lacking the expertise that only a doctor, specifically a women's health specialist, can fully comprehend and is trained to navigate.

Mae Winchester, MD: A patient very dear to me, who I'll call Amanda, managed to schedule time away from her three jobs to see me one morning. Several years ago, she had an abnormal pap smear, but lost her health insurance and was unable to afford a follow-up visit with a doctor. By the time I saw her, she had developed invasive cancer – her cervix had been essentially replaced by a large tumor. She was also 14-weeks pregnant. As a physician specializing in high risk pregnancies, I know that treatment for this advanced of a cancer requires termination of pregnancy, because a fetus cannot continue developing amidst chemotherapy and radiation. She wanted nothing more than to be able to continue the pregnancy. She thought long and hard about her diagnosis and had open, compassionate discussions with her family. She told me that her children, one still in grade school, begged her to have an abortion so that she might live to see him graduate high school.

We talked about what a pregnancy with cancer looked like – of the risks of continuing the pregnancy, not only the significant decrease in her life expectancy should cancer treatment be delayed, but also the incredibly real threats of a preterm delivery with its severe consequences for the child. Though she was not actively dying, her life was at risk. Through tears, she told me she felt she needed an abortion. Amanda subsequently had an abortion and promptly started treatment for her cancer. I saw her many months later, in the hospital, when she was getting one of her cancer treatments, with her family by her side. Through tears, she told me she still grieves her baby every day. When I told her how my heart breaks for her, she held up her arm to hug me and said, "It's ok, thank you for saving my life"…I oppose any legislation that endangers access to comprehensive reproductive health care. Patients should be allowed to make complex medical decisions that align with their faith, their family needs, and their health, without interference from the government. Abortion is an incredibly personal decision and should be treated as such.

Emily Martinelli, MD: As an obstetrician and gynecologist, it is my responsibility to be on the lookout for potential subtle changes that my precede a devastating outcome…There is a wide spectrum of hypertensive disorders of pregnancy which can cause organ damage such as kidney failure, severe lung disease, stroke, blindness, seizure, and sudden fetal death. . .

My patients need to have safe access to abortion care. Without this fundamental human right of medical care, women are at increased risk of death simply by being pregnant, not to mention the increased literal and emotional cost associated with pregnancy…Safe abortions are an integral part of health care. Protecting the right to safe abortion care for the women and families of Kansas is a vital part of keeping Kansas a healthy and safe state for pregnant patients to live.

Selina Sandoval, MD: I would like to tell you the story of a patient of mine, we can call her Sarah. I took care of Sarah very recently. Sarah presented to the hospital with an unrelenting headache. It was discovered that her blood pressure was severely elevated, putting her at risk for stroke and death. Sarah knew she was pregnant. An ultrasound confirmed a twin pregnancy. One of her twins was a normally formed viable pregnancy. The second pregnancy however was abnormal and released dangerously high levels of pregnancy hormones. This condition can cause heart failure, cancer and if untreated, death.

Sarah was transferred to the medical ICU, where multiple medical specialists were involved in her care. It was agreed by these specialists that an abortion was the safest course of action for Sarah. This was difficult for Sarah, as this was a highly desired pregnancy, and she feared judgement from others. She was forced to make the impossible choice between her life and her baby's life. This was a personal and private medical decision. With the support of her husband, her chaplain, and her medical team, Sarah made the decision to proceed with her abortion. Sarah left the hospital on the road to recovery and still one day hopes to have a family of her own.

Thankfully, it was legal for Sarah to obtain her abortion. However, legislation such as SCR 1613/HCR 5019 directly threatens this right. Sarah and all of the physicians caring for her knew what was best for her health care. SCR 1613/HCR 5019 would make it possible for the state of Kansas to put even more restrictions on a woman's access to abortion care with no regard to the health and safety of Kansas women and families.

Angela Martin, MD testified before the House committee earlier this month. Submitted photo.

Angela Martin, MD, FACOG: As a high-risk obstetrician working in Kansas . . . I manage complicated pregnancies. My goal is always to have a healthy mom and baby. In that regard, I am very "pro-life"! Most of the time, my colleagues and I can accomplish the goal of a healthy mom and baby.

However, there are scenarios when delivering a healthy baby from a healthy mom is unattainable. Families from all across the state of Kansas are referred to my practice. Many times, they have just been given the worst news of their lives. Their dreams have been shattered and they are terrified. They are left to make one of the hardest decisions they will

ever be faced with. I am honored that mothers and families allow me to help them through this vulnerable and terrifying time. I will share with you a few scenarios that I hope lawmakers never find themselves (or their loved ones) in. If they do, however, I hope they too have abortion as an option . . .

Erin and Jake struggled to get pregnant. They tried for 2 years before seeing a specialist. There had never been a more desired pregnancy. They were sent to me at 21 weeks, 1 week after their OB doctor told them they the baby didn't have any amniotic fluid on ultrasound. Being excited and optimistic (as most new parents are), they figured this maybe meant they were considered "high risk", but they continued to picture their baby girl at home with them in 4 short months. They were talking about the nursery design when I walked into the room to speak with them. Their baby had bilateral renal agenesis; no kidneys. The lack of amniotic fluid was because the baby couldn't make fluid without kidneys.

This diagnosis cannot be made until after the first trimester when the fetal kidneys are expected to start functioning. Outside of the first trimester, most women don't get ultrasounds until around 20 weeks, meaning this is almost always a mid-second trimester diagnosis. Without amniotic fluid, the lungs don't expand and develop in-utero as they should, and the small or "hypoplastic" lungs are incapable of sustaining life outside the womb. Without adequate lungs or kidneys, survival is impossible. This is a lethal diagnosis. I knew I was about to shatter their whole world. After hours of discussing the diagnosis and management options, they went home to consider their options even more.

When Erin and Jake returned a few days later and had decided on an abortion she told me something that was so wise, I still use her words to help people understand why parents might choose this gut-wrenching option. She said "I couldn't bear the thought of delivering her just to watch her struggle to breath and survive. I think that would be the more selfish choice… I want to stay pregnant, I want the chance to hold her. I'm not ready to say goodbye to her. But I know the more compassionate choice would be to end the pregnancy now, while she is still comfortable, before she has to suffer in this world." On the day of the procedure, I spoke with her before she went to the operating room. Again, her bravery to make the more compassionate yet more difficult choice left me humbled. "It gives me a little comfort to know that the only existence she will know is the comfort of growing inside me. I think I've made her happy in there."

Amber had one child. After delivery of that first child, she developed a cough and had some shortness of breath. Her legs began to swell. She was so wrapped up in the nightly snuggles, breastfeeding schedule, and continuous stream of family and friends coming to visit her new arrival, that she didn't have time to think much about it. I am so grateful the pediatrician noticed her struggling for air and the edema in her legs while she was at an appointment with her baby girl 1 week after delivery. The pediatrician advised Amber to go straight to the hospital

where was found to be in congestive heart failure – her heart was failing, a condition known as
postpartum cardiomyopathy. She was admitted to the ICU and put on several medications to maintain her blood pressure and help her dilated heart pump. She has not and will never fully recover from this and she requires daily medications. Given the severity of her heart failure and lack of a full recovery she was counseled that the risk of recurrent heart failure in subsequent pregnancies was very high. Recurrent postpartum cardiomyopathy could be so severe she could require a heart transplant, or even die. To prevent pregnancy, she opted for a very effective form of contraception. She had an intra-uterine device (IUD) inserted. The IUD also prevented her from having regular periods, which is why she didn't even consider
pregnancy as an option when she started feeling nauseous a few years later. When the "GI bug" didn't go away after a few months, she saw her primary care provider, who determined that despite use of an effective contraceptive, she was pregnant. She was 17 weeks when I saw her in my office. She told me "I always wanted Avery to have a brother or sister, but I don't want her to have a brother or sister instead of a mom." Her abortion 2 days later allowed her daughter to grow up with a healthy Mom.

Jill recently moved to the area with her husband and three kids. She had good prenatal care, with a normal ultrasound in the first trimester. When she presented to my office at 19 weeks for her routine birth defect screening ultrasound, she was given some devastating news. While her baby boy looked healthy, her placenta was very abnormal. Her first three children were born by cesarean section. After multiple cesarean sections, the placenta can sometimes invade the uterine muscle (and beyond), a condition known as placenta accreta. Prolonging the pregnancy put her at risk for life-threatening hemorrhage. Understandably, Jill did not want to end her pregnancy. We ordered an MRI to get a better idea of the severity of the placental growth in her abdomen, but 2 days later, and before the MRI was done, Jill came into the hospital hemorrhaging. She required an emergency surgery to remove the bleeding placenta and uterus. Unfortunately, 19 weeks is too early for a fetus to survive outside of the womb, and therefore Jill lost her baby. Had we kept her pregnant because of the healthy 19-week baby growing along with her invasive placenta, she would have died. Because of the abortion, Jill lived. The surgery was 8 hours long and Jill required over 60 units of blood products to save her life. Despite a long recovery in the ICU, she was able to go home to her 3 children and husband.

Katie and her husband were also expecting their first baby. They lived in rural Kansas. At 8 weeks her OB noted a small fetus in the uterus. Nothing seemed amiss. Her next routine ultrasound was scheduled around 20 weeks to screen for birth defects. Katie was 20 weeks and 3 days when she was told her baby was severely growth restricted and the placenta appeared abnormal. Also, her blood pressure was extremely elevated. She had been feeling jittery, had started getting headaches, and had some heart palpitations over the past several weeks that she

attributed to normal pregnancy. Based on her symptoms and ultrasound findings, her OB was suspicious of a molar pregnancy. When we saw her the next day, we confirmed the diagnosis. She had a partial molar pregnancy. Partial molar pregnancies are
triploid, meaning they have 3 copies of each chromosome instead of the normal 2 copies. The fetuses of partial molar pregnancies cannot survive. Even when carried to a gestational age when survival is expected, they die shortly after birth. Most of these pregnancies end spontaneously in early miscarriage, but occasionally they continue, and when they do, there is potential for great harm to the mothers. Partial molar pregnancies are at very high risk of hypertensive disorders that can cause stroke and seizures. Katie was already showing signs of a hypertensive disorder. These pregnancies can cause hyperthyroidism, which Katie did have, causing her racing heart and palpitations. We admitted Katie to the hospital. Over the next 2
days, her blood pressure became so high her kidneys began shutting down. She had the best care in the ICU and received all possible medications to keep her safe. But her life was at risk and she was carrying a baby that would not survive. I will never forget what she said when she signed the consent form for an abortion: "I am pro-life, I never dreamed I would ever make this decision." Her abortion was performed at 21 weeks and it saved her life.

88% of abortions are done at or before 12 weeks, ~ 4% are performed at 16-20 weeks, and only 1.3% are done at 21 weeks or beyond. These scenarios I have described represent the minority of abortion procedures done. But perhaps they are some of the most important. None of these women ever pictured having to end their pregnancies with an abortion. It wasn't what they wanted. I have never seen a woman make the decision to terminate her pregnancy in the late second trimester without a lot of thought, tears, heart break, and often prayer. Please protect access to abortion as a fundamental right for all of the women I will see in similar situations in my future.

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