Approved: 3/15/11
Date

MINUTES OF THE HOUSE FEDERAL AND STATE AFFAIRS COMMITTEE

The meeting was called to order by Chairman Steven Brunk at 1:30 p.m. On February 17, 2011, in Room 346-S of the Capitol.

All members were present except:
Representative Rocky Fund – Excused
Representative Mike Kiegerl – Excused
Representative Charlotte O'Hara – Excused
Representative Mike Peterson – Excused

Committee staff present:
Mike Heim, Office of the Revisor of Statutes
Doug Taylor, Office of the Revisor of Statutes
Julian Efird, Kansas Legislative Research Department
Dennis Hodgins, Kansas Legislative Research Department
Stephen Bainum, Committee Assistant

Conferees appearing before the Committee:
Tiffany Campbell
Amber Versola, Kansas NOW
Virginia Philips, Trust Women
Sarah Gillooly, Planned Parenthood

Others attending:
See attached list.

The Chairman called for bill introductions. Representative Kinzer introduced a House Resolution to join the health care lawsuit. Secondly, he introduced a bill for the integration of E-verify and law enforcement. They were both accepted without exception.

The Chairman re-opened the hearing on **HB 2218** **Abortion regulation based on capacity of unborn child to feel pain** to hear those opposed the bill.

Virginia Phillips of Trust Women presented an audio-video testimony of Miriam Kleiman and Jason Steinbaum. It would be available from Trust Women. Miriam Kleiman's Written Only testimony is listed below.

Tiffany Campbell presented testimony as an opponent of **HB 2218** (Attachment 1). She was pregnant with twin boys who were suffering from Twin-to-Twin Transfusion Syndrome. At 17 to 18 weeks gestation they terminated one twin so that the other would survive. Tiffany maintains that this bill would prevent that if it was not discovered by the 21st gestational week.

Representative Grosserode asked what the gestational age was when they terminated one of the babies? Tiffany said it was about 17 weeks and they were referred to one of the top fetal care centers in the country, we had two days of testing and then it was at 18 weeks the life of one twin was terminated.

Representative Rubin said that the criminal sanctions in this bill would never apply to the mother of the child, are you aware of that. Tiffany said that she was aware of it and that it would apply to the doctor. She said that a woman would never be able to find a doctor who would risk his license to help her.

Representative Huebert said that this bill would not have impacted you at the 18 week gestational period you were at. Tiffany agreed that it wouldn't especially since she does not live in Kansas. Representative Huebert said that there were new technologies which will now give more options in the future.

Amber Versola, Kansas NOW, presented testimony as an opponent of **HB 2218** (Attachment 2). She said that this bill takes the rights of women to make personal medical decisions and places it in the hands of this legislative body. This bill fails to take individual medical circumstances into consideration. She said that the American College of Obstetricians and Gynecologists knows of no evidence that fetuses experience pain at this stage. The British Medical Journal has stated that fetuses do not feel pain until 26 weeks. She concluded that this legislation lacks empathy for pregnant women. This bill vilifies women and is an affront to the pain, the loss and the mental anguish these women endure.

Representative Patton took objection to one comment. He said that you have not heard anyone on this committee vilify women. What we have heard is their attempt to vilify politicians. The subject here is human life and the state has a legitimate interest in these debates, but you have not heard anyone here vilifying anyone. Do you know of any other law that allows a person to take human life or the life of a disabled person merely because their motive was based upon love? You mentioned unspeakable pain. What about the unspeakable pain of the unborn child that's based on evidence we heard yesterday?

Representative Goico said that the issue is very narrow. It is when does a baby have the ability to feel pain? He said that none of her testimony addressed that.

Representative Seiwert said there had been some touching testimony of parents having to deal with the having to make a decision whether they live or not? Have you ever sit in a hospital with an aging parent that was dying and was in terrible pain. Amber said she had. Representative Seiwert asked if you were ready to pull the plug on them? Amber did not feel comfortable answering that question.

Representative Rubin asked if she had statistics regarding what percentage of abortions performed at 22 weeks and beyond are for reasons such as you have testified about today as opposed to abortions performed for no such medical reason? Amber said that she understood that at 22 weeks you could not get an abortion except for reasons of the mothers health. Representative Rubin said that we are talking about medical problems with the fetus. Amber did not have those statistics.

Representative Loganbill said that KDHE would have that information.

Representative Brunk asked if we were to change this bill to exclude fetal problems in the mothers womb that involved a serious medical emergency would that change you from an opponent to a proponent? Amber said you would have to be very clear as to what constituted a life threatening condition. Representative Brumk asked if it was a perfectly healthy child, would that change your testimony? Amber would not answer that question.

Representative Gregory asked if she was aware that in Section 3 **HB 2218** would allow an abortion on a woman when the gestation age was 22 weeks or more if there is a reasonable medical judgment that she has a condition that complicates her medical status. Amber said that it did not consider her mental health and it does not make an exception for fetal anomaly.

Virginia Phillips presented testimony as an opponent of **HB 2218** (Attachment 3). She recounted the cases of several women who terminated their pregnancy past 22 weeks because of severe fetal anomalies. She said that the AMA says that evidence regarding the capacity of a fetus to feel pain is limited and that it is unlikely that they feel pain before the third trimester.

Representative Brunk asked that the information from the AMA be supplied to the Committee Assistant. Virginia said that she would supply it.

Representative Gregory asked if this bill had an amendment that would have an exception for a child in uterus that had an anomaly in development, would you support it? Virginia said that she was not in a position to answer that and that a ban on pre-viable fetuses is unconstitutional.

Representative Patton asked what the year of the quote from the AMA was. Virginia said she did not have it right now but would provide it.

Sarah M. Gillooly, Planned Parenthood of Kansas and Mid-Missouri, gave testimony as an opponent of **HB 2218** (Attachment 4). She stated that **HB 2218** was unconstitutional for three reasons; 1. it bans pre-viability abortions, 2. it fails to state a constitutionally recognized state interest, and 3. it fails to adequately protect a woman's health.

Representative Huebert said that a lot has changed since 2005 in medical science. Is there medical knowledge now that might be more relevant? Sarah said that she could submit more recent information.

The following written only testimonies are personal experiences of abortions performed because of fetal anomalies. They are all submitted as opponents to **HB 2218.**

Miriam Kleiman (Attachment 5).
Melissa Hamilton (Attachment 6).
Christie Brooks (Attachment 7).
Susan (no last name) (Attachment 8).
Michelle (no last name) (Attachment 9).
Carmin Bullock (Attachment 10).
Melissa (no last name) (Attachment 11).
Alesha E. Doan (Attachment 12).
Stephanie Imbesi (Attachment 13).
Heather S Pew (Attachment 14).
Tracy Petruso (Attachment 15).
Jill Meadows M.D. (Attachment 16).

The next meeting is scheduled for February 18, 2011.

The meeting was adjourned at 2:57 p.m.

HOUSE FEDERAL AND STATE AFFAIRS COMMITTEE

2.17.11

ROOM 346-S

NAME	REPRESENTING
Denise Cochran	CWA
Edward Larson	KS Catholic Conference
Ken Zweig	me
Jennifer Weishaar	myself
Virginia Phillips	Trust Women PAC
Aimee Rosenow	Intern - O'Brien
Taylor Zimmerman	Intern - Wolfe Moore
Ted Henry	CS.
Jacklyn Ratliff	Planned Parenthood
Sarah Gillooly	~~S~~ PPKM
Laurie L. Moore	citizen
Sheila Kostas	PPKM
Jean Rosenthal	self
Lenett Compton	self
Sue Storm	self
Bob Eckhardt	Self
Kylie McAllister	Rep. Loganbill
Jeanne Gawdun	KFL
Kathy Ostrowski	KFL

2/16/11

TO: Kansas House Federal and State Affairs Committee

FR: Tiffany Campbell

RE: HB 2118 OPPONENT

Good afternoon committee members. My name is Tiffany Campbell, and I'm a mother of three, **former Olathe resident, testifying in opposition to HB 2118.** My husband Chris and I, in consultation with our doctors, made the difficult decision to have an abortion in 2006. We did it so we could bring our youngest son into this world rather than burying two babies. Here's what happened.

Chris and I were happily married with two children and looking to add to our family when we became pregnant. We were thrilled. Then, I landed in the hospital with a severe kidney infection and received my first ultrasound. We were overjoyed to see we were expecting identical twin boys.

But then we learned that our sons were suffering from a severe case of Twin-to-Twin Transfusion Syndrome, a condition where twins unequally share blood circulation. One boy was receiving too much blood resulting in a strained heart and acute risk of heart failure. Meanwhile, his brother was clinging to life, but his blood supply was insufficient to sustain normal development. This is an affliction where if one twin dies, the other faces significant risk of death. In fact, severe TTTS has a 60-100% fetal, or neonatal mortality rate.

My husband and I were sent to one of the premier fetal care centers in the country and told our only hope for saving this pregnancy was to have a selective termination on the one of the babies, and hope the other twin would survive.

So we were faced with an awful situation that forced us to examine our most fundamental moral and spiritual beliefs. At first we just didn't want to believe the doctors' prognosis. We wanted so badly for our boys to win the fight. But we couldn't stay on the sidelines forever: against all of our hopes and prayers, our twins' conditions continued to deteriorate quickly.

This was the most difficult decision of our lives. We could let nature run its course and pray that by the grace of God our boys would miraculously survive, or we could abort the sicker of the two, giving his brother a legitimate shot at life.

We decided to abort one of our sons at 18 weeks. Our decision was predicated on consultation with experts in the field of fetal medicine, our personal beliefs, prayer, and a mother's intuition.

This was an excruciating decision for us to make. But, it would have been unimaginably worse if our decision had been criminalized. Under Kansas HB 2118, a woman who may not find out about a condition such as mine until her 21st gestational week would have no time to contemplate this most difficult of decisions, for she would be working against a clock that would deem her a criminal at 22 weeks.

Under HB 2118, a woman at 22 weeks with my condition would be forced to go against her better judgment and against the sound medical advice of her physicians -- facing the probability that she would bury two babies.

If HB 2118 is passed, Kansas women and their families will be stripped of their right to make this private medical decision in consultation with their doctor and clergy. Instead, the government would be dictating a family's personal choices.

Today we have a **healthy four-year-old boy** who is the treasure of his older brother and sister. He's the family jester, the optimist, the one with a quick smile and a contagious giggle. It's like he made a pact with his twin brother to live passionately -- to live for both of them in honor of the spirit of his fallen brother.

Everyday our youngest son's contagious giggle reminds us that we made the right decision for our family. Let God be our judge. Please vote no on HB 2118.

Thank you for hearing my family's story.

Kansas NOW
Amber Versola, Lobbyist
Phone (785) 979-1733
lobbyist@ksnow.org

PO BOX 1860
Wichita, KS 67201

KANSAS
NATIONAL ORGANIZATION FOR WOMEN

2/16/2011

TO: Kansas House Committee on Federal and State Affairs

FR: Amber Versola, Lobbyist – Kansas National Organization for Women

RE: HB 2218 Opponent

Kansas NOW respectfully opposes HB 2218. This bill is an intrusion by the government into a very private decision, a decision that rightfully belongs only to a woman, her family, and her physician. This bill ensures the growth of "big government" in Kansas by taking the right to make personal medical decisions away from a woman and her family – and places it in the hands of this legislative body.

- Kansas NOW contends that each individual pregnancy has its own unique characteristics. What is right for one woman and her family is not right for all women. This bill fails to take individual, medical circumstances into consideration.
- Dr. Anand, the physician whose study this legislation is largely based upon has gone on record as stating that *"he does not oppose abortion in all circumstances but says decisions should be made on a case-by-case basis."*[1]
- The American College of Obstetricians and Gynecologists has stated that it knows of no legitimate evidence that fetuses experience pain at this stage. *JAMA* has stated that it is unlikely that a fetus will feel pain until the third trimester. According to the British Medical Journal, it is unlikely that a fetus will feel pain until 26 weeks, if at all. These are reputable medical associations and publications that have made and stand by such claims.
- There is no proof that enacting this legislation would save the life of any fetus or contribute to a higher standard of healthcare for pregnant women.

Quite simply, this legislation lacks empathy for pregnant women and their families who should be supported and comforted during the most painful moment of their lives. This bill vilifies women and is an affront to the pain, the loss and the mental anguish these women endure. Kansas NOW trusts women and knows that women are capable of making important, personal medical decisions without government intervention.

Abortion is often sought as a way to prevent the suffering of a woman and her family, rather than exposing what they hold so dear to a short lived life wrought with painful and terminal conditions. If we truly cared about the fetus, we would allow a loving parent to alleviate the suffering of their wanted and loved pre-born child.

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[1] Annie Murphy Paul, "The First Ache," *New York Times*, February 10, 2008, http://www.nytimes.com/2008/02/10/magazine/10Fetal-t.html?pagewanted=1&_r=1 (accessed February 16, 2010).

Kansas NOW asks that you consider the testimony submitted by Carmen, Christie, Heather, Michelle, Stephanie and Tiffany. Please take these personal accounts into careful consideration and in the spirit of decency and empathy for them and countless other women reject HB 2218.

Sincerely,

Amber Versola

Kansas NOW Lobbyist

Chairman Brunk
House Federal and State Affairs Committee
Meeting Time: 1:30PM Location: 346-S
Topeka, KS

Dear Chairman Brunk and Committee Members:

Thank you Chairman Brunk and Members of the Committee for allowing me to testify today in opposition to HB 2218. My name is Virginia Phillips and I work with Trust Women, a reproductive health and justice organization.

Today, I will relay to you the stories of eight brave pregnant women who were willing to share their difficult, private, family decisions in defense of Kansas women and their families' right to decide what is best for them.

These eight women could be our friends, sisters, mothers, wives,--our children's pre-school teacher, a nurse in our doctor's office, the young mother seated next to us in church. Each woman, in consultation with her physician—often in consultation with several physicians for the purpose of multiple opinions—chose to end her pregnancy past 22 weeks. Each of these pregnancies was a wanted pregnancy and each woman also found out that her baby was diagnosed with a severe fetal anomaly- including severe hydrocephalus, Turner's Syndrome, severe heart failure and abnormal formation of organs, congenital diaphragmatic hernia (CDH), Heterotaxy Syndrome and hypoplastic left heart syndrome. These may not all be familiar terms, but in each instance, these diagnoses meant that physicians were surprised the baby was still alive at all and that it would either die before full term or die almost immediately after birth.

Of the women-Mindy, Miriam, Melissa, Christie, Susan, Michelle, Carmin and Melissa- most were scared of their future reproductive abilities due to complications of pregnancy; they wanted to have another baby and were worried that without terminating, they would risk their fertility. Each described the decision as heart-wrenching in her own words, but also noted that this was the unselfish decision - a decision they all made as parents. *As Susan put it, they "loved their babies as much as any other parent. We did not want them to suffer..."*

"I want to have more children. I want several children. I want to have a full, happy home. But at this point, all I could think was that I would probably lose my uterus--and all in vain. If it was for a baby that might live, it might be worth it...but it wasn't," explained Mindy of her fear and frustration with the situation.

"If we did nothing, we would be on a "death watch," merely waiting for our baby to die, and that was totally unacceptable to us...I was prepared to go anywhere, at any expense, and at medical risk, to end our anguish. We loved our baby too much to suffer the misery of waking up every morning awaiting his impending death. We had been told that even if our baby had been born alive, he would face certain organ failure and would be put through painful surgeries and interventions for months and months--and then still would die. And given that our baby was going to die anyway, we didn't want him to suffer," wrote Miriam.

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"Termination for medical reasons is a horrible choice no parent wants to make, but it should not be limited," asserted Melissa, a nurse.

"Over the years since her passing, I have often contemplated what life would have been like had I not been given the option to end her suffering early. The remaining four months of my pregnancy would have been torturous--not only in having to deal with questions from others about the pregnancy and the baby's arrival, but in having to prepare my 2-year-old for the death of her little sister. Being forced to carry a doomed pregnancy to term would have devastated my family greatly, not only emotionally, but financially and spiritually as well," said Christie of her thoughts since ending her pregnancy, the pregnancy of a wanted, loved child.

"Being Catholic, this decision was wrought with the added guilt that I would be surely going straight to hell. I sought out the priest who married us and asked for his guidance prior to the termination. He gave me great comfort and assurance that our baby boy was in a better place and that our decision was based on our deep love for him as it was in his best interest," told Michelle of her consideration of her Catholic faith during her decision.

I ask that, on behalf of the health and safety of Kansas women - our mothers, sisters, wives, daughters, friends and community members - that you do not support HB 2218. This bill removes the ability of pregnant women and families to make critical decisions about pregnancy in consultation with their physicians. The bill puts lawmakers in the position of health care administrator and decision-maker and bans safe, legal procedures. This is nothing more than political interference in a pregnant woman's most personal, private medical decisions.

The women who will be adversely affected by HB 2218 are women whose pregnancies went horribly, irreversibly wrong. HB 2218 may, in some cases, take away a woman's ability to have children in the future by refusing her needed medical care. I don't believe that the legislature intends for women's fertility to be sacrificed for political gain. This is why we must be mindful of the fact that pregnancy is not a "one-size-fits-all" situation - each woman is different, with different medical needs, and each pregnancy is different as well. We must honor the differences in each woman and the physicians - OBGYN's, Family Physicians, Perinatologist, Maternal/Fetal Medicine Specialists - who strive to provide sound care and counsel to the women who present before them.

I urge the Committee to allow women and their families, in consultation with their physicians, to make the decisions that are best for them. I urge the Committee to carefully weigh the consequences that women will face and be forced to endure if they are not allowed to make medically sound and reasonable decisions about their pregnancies. I urge the Committee to consider the pregnant women and their partners who have to walk through these life decisions - as parents.

Thank you for hearing my testimony today.

Sincerely,
Virginia L. Phillips

Planned Parenthood®
of Kansas and Mid-Missouri

Testimony of Sarah M. Gillooly, M.A.
Kansas Public Affairs Manager of
Planned Parenthood of Kansas & Mid-Missouri,
in opposition to House Bill No. 2218 before the
House Federal & State Affairs Committee
of the Kansas Legislature
February 16, 2011

Good afternoon. My name is Sarah M. Gillooly and I am the Kansas Public Affairs Manager for Planned Parenthood of Kansas and Mid-Missouri. Thank you for this opportunity to present testimony in opposition to HB 2218. In Kansas, Planned Parenthood maintains family planning health and education centers in Wichita, Hays and Overland Park. Our most important goal is to help men and women make responsible choices that prevent unintended pregnancies and sexually transmitted infections. More than ninety percent of our patients come to our agency for family planning and other preventive health services. At our Comprehensive Health facility in Overland Park, we also provide safe and legal abortion care. We do not provide abortions after 21 weeks gestational age, which is the timeframe contemplated in this bill. Also attached to my written testimony is a memo from Former Acting Solicitor General Walter Dellinger regarding the constitutionality of Nebraska LB 1103, on which KS HB2218 is modeled.

I am here today to explain why Planned Parenthood of Kansas and Mid-Missouri opposes HB 2218. First and foremost, we oppose HB 2218 because it is unconstitutional as written in 3 separate ways: (1) it bans pre-viability abortions, (2) it fails to state a constitutionally recognized state interest, and (3) it fails to adequately protect a woman's health.

On the first point, according to *Planned Parenthood v. Casey* (1992), the U.S. Constitution prohibits a state from enacting a law that bans abortion prior to the point in the pregnancy when a fetus is viable. Furthermore, in PP of Central *Missouri v. Danforth* (1976), the Supreme Court held that the "determination of whether a fetus is viable is, and must be, a matter for the judgment of the responsible attending physician."

Also in *Danforth*, the Court specifically rejected as unconstitutional laws which provide for a fixed gestational limit on when abortions can be performed. The court reasoned: "Because viability may differ with each pregnancy, neither the legislature nor the courts may proclaim one of the elements entering into the ascertainment of viability – be it weeks of gestation or fetal weight or any other single factor – as the determinant of when the State has a compelling interest in the life or health of the fetus." So, because this bill sets a gestational age when abortions are to be banned, and does not permit the responsible attending physician to determine whether or not the fetus is viable – HB 2218 is unconstitutional.

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Secondly, the bill fails to state a constitutionally recognized state interest. To date, the U.S. Supreme Court has only ever recognized two state interests that are sufficient to override a woman's ultimate decision to terminate a pregnancy. Those two state interests are either (1) the preservation of the potential life represented by a viable fetus, or (2) regulation necessary to protect the health of the women undergoing the medical procedure. The interest asserted by the State of Kansas in this bill is neither of these.

And third, HB 2218 is unconstitutional because it fails to adequately protect a woman's health with an appropriate exception. The Supreme Court has long held that even after viability, when a state may prohibit abortion, the prohibition must make exceptions for where the abortion "is necessary, in the appropriate medical judgment, for the preservation of the life or health" of the woman. The exception in HB 2218 only applies when a continuation of the pregnancy will cause a substantial and irreversible physical impairment of a major bodily function." This exception language is too narrow to pass constitutional muster and threatens the health and safety of pregnant women in Kansas.

There is, of course, one outlier in the discussion of health exceptions, and that is the 2007 decision of *Gonzalez v. Carhart*. It is imperative to recognize, however, that in holding that a health exception was not required in that federal legislation, the Court ruled that to be true only because they were banning a particular method of performing an abortion, and not making abortion unavailable. There were other methods of an abortion available to the woman – which would not be true in the instance of HB 2218.

To repeat – this bill is unconstitutional for 3 reasons: (1) it bans pre-viability abortions, (2) it fails to state a constitutionally recognized state interest, and (3) it fails to adequately protect a woman's health.

In addition to the unconstitutionality of HB 2218, Planned Parenthood of Kansas and Mid-Missouri opposes this legislation because it is an attack on pregnant women and their families. Women facing medically complex pregnancies, such as those with severe fetal indication, often have no knowledge of the complications with their pregnancies until 18 to 20 weeks gestation. Under HB 2218, women would be forced, and to some extent coerced, by the state to make rushed decisions whether to continue their pregnancies or not in the face of fetal anomalies incompatible with life or fetal indications that jeopardize the life of one or more multiples, such as Twin to Twin Transfusion Syndrome. If the Kansas legislature is truly concerned with the health of pregnant women, you will reject HB 2218.

In closing, Planned Parenthood asks this Committee to oppose HB 2218 because it is clearly unconstitutional, potentially embroiling the state in years of expensive litigation, and jeopardizes the health and safety of pregnant women. HB 2218 does not, and cannot, take into account the complex realities of each individual pregnancy. The cruel irony of HB 2218 is that women who need help the most will be the least likely to get it. HB 2218 does nothing to reduce the need for or number of abortions in Kansas, but instead places women in peril.

TESTIMONY OF MIRIAM A. KLEIMAN

My name is Miriam Kleiman. I am 42 years old. I have been happily married to my husband Jason Steinbaum for 12 years. We have two boys ages 6 and 8. My husband works on Capitol Hill, where he is Staff Director for a House subcommittee. I work for the federal government, and I am a soccer mom.

In July 2000, I was pregnant with another much-wanted child. My husband and I had been married three years and were excited and ready to be parents for the first time. We had selected furniture, car seats, and other items to help us keep our baby comfortable, warm, protected, and loved.

I took prenatal vitamins. I did not drink. I have never smoked. I avoided sushi, artificial sweeteners, deli meats and cheeses. I had all the usual tests, and everything was normal. However, late in my pregnancy, my OB. said I was "carrying large" and suggested one last sonogram "just to make sure" things were O.K. I assumed that this sonogram would be another joyous look at the baby, and insisted that my husband come to share in the excitement and happiness of seeing our baby.

The sonogram technician, however, immediately detected severe problems. The OB was called in at once to tell us that the condition was extremely grave. We were transformed from happy, expectant parents to devastated, panicked people in immediate need of advice and options. We were rushed to a variety of hospitals where I was examined by several doctors. All told us that the baby had major brain abnormalities, including severe hydrocephalus and a malformed vein of galen, and that these problems had affected the baby's heart and lungs, as well. We were told our precious baby boy would die at some point in utero or immediately after birth.

Our world was shattered, and we needed to find a way to pick up the pieces. After our consultations with these specialists, it was clear that there was no medical miracle to correct the baby's condition. Worse still, our doctors informed us that abortion was not an option because the pregnancy was past the legal limit for termination. They said I had no choice but to wait and deliver our baby at term as if the pregnancy were proceeding "normally." Third trimester abortions, they explained, are just not done.

Desperate, we begged the head of our obstetric practice for any other options. He calmly explained that there were none—that I had no choice but to carry the baby more than two more months until delivery at full term unless the baby died in utero before that. We directly asked him about the possibility of termination. Our doctor glared at us and responded succinctly: **"We call that murder."**

We loved this baby boy too much and were too attached to him to suffer the misery of waking up every morning awaiting his impending death. We made the dreaded phone calls to inform our parents that their long-awaited grandchild would not survive. Because

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Jason's father and sister are physicians with a network of colleagues, we learned that we had actually received incorrect information. There was, in fact, an option. We wrote down the name of a doctor in the far away city of Wichita, Kansas, but refused to give up hope.

We grasped for second, third and fourth opinions as we went from hospital to hospital. The radiologist we visited repeated the grim prognosis: The baby would die in utero or within days of birth. My husband turned to him and asked: "if this were your wife, what would you do?" He responded: "I would find any way possible to terminate the pregnancy."

We then met with a leading perinatologist – to see if there was anything that could be done in-utero to correct the abnormality or repair the brain, heart or lungs. She had reviewed our file, and told us the damage was too severe - nothing could be done. She asked if we had any questions. I said that we wanted to terminate the pregnancy, and asked if she knew of any way to do so. She stared at us in shock and asked accusingly: "You just found out. How can you make such a decision?"

We said that we had thought of nothing else since the sonogram the morning before – that we hadn't slept, or read the paper, or watched TV. – we had done nothing but cry and think of our precious son.

We shared that if we did nothing, we would be on a "death watch," merely waiting for our baby to die, and that this was totally unacceptable to us. I told her that personally, I was prepared to go anywhere, at any expense, and at medical risk, to end our anguish. We loved our baby too much to suffer the misery of waking up every morning awaiting his impending death. We had been told that even if our baby was born alive, he would face certain organ failure and would be put through painful surgeries and interventions for months and months—and then still would die. And given that our baby was going to die anyway, we didn't want him to suffer.

This woman listened, and excused herself from the room. We waited. And waited. She came back a few minutes later with a scrap of paper – not hospital stationary, nothing with her name or the hospital's name on it – just a torn scrap, on which just four words were written: "Dr. Tiller, Wichita, Kansas."

We left for Kansas two days later. We were treated with kindness, warmth, and respect by everyone we met at Women's Health Care Services. I was again examined, and my file was again reviewed. We were given counseling and support. The procedure was explained, and we were consulted at each step of the process. I have never met kinder or more caring people.

For the record, my abortion was performed in August 2000. After the delivery, my husband and I, along with our mothers, held our intact baby, said a blessing, and bid him goodbye. He is buried at a cemetery in Northern Virginia, and we visit often.

5-2

We feel a strong obligation to tell our story to inform others of why it is necessary to preserve the right to choose. In doing so, we also feel we are remembering the baby we lost, but still hold dearly in our hearts. It is hard to stress strongly enough that we did NOT "change our minds" about being parents. This was a desperately wanted child. one who had been planned for, dreamed of, read and sung to. and long-hoped for. The hardest thing to convey is how much my husband and I did love our son, how we remember him and mourn his loss, but how we made a decision that we thought would be more humane. And I fear that other women and families may not have that option in the future.

I had left my job with a private company and was going to stay home, to be a mom. I had switched to Jason's government health insurance. Government insurance does not cover abortions. even when medically necessary. Fortunately, through COBRA, I was able to remain on my office's private insurance policy plan. and the entire procedure was paid for.

While I hope and pray that no one has to go through what my husband and I have, I know there are people who will. It can happen to anyone—to you, your wife, your sister, your daughter, your friends. There will be families in the future faced with this tragedy, and they deserve the protection, the guidance and the access that modern medicine allows. And they deserve the insurance coverage needed for this health service.

Losing our baby was the hardest thing that we have ever experienced. But I am grateful that Jason and I were able to make this difficult decision ourselves, that we had both this medical option. and the insurance care to cover this procedure.

It is my hope that someday in the future when brave doctors like the late Dr. Tiller and their staffs face harsh rhetoric from the so-called "right to life" movement or hear about ill-advised congressional restrictions on a woman's right to choose, they will not see the anger of the anti-choice activists, but will envision instead of face of our healthy sons whose picture we sent each year to Dr. Tiller - and will know that what they did for my family, and many others. was right and helped us reach this day.

5-3

Here is our story. We wanted a 2nd child. We got pregnant right away, and then had an early miscarriage. My husband Adam and I were crushed. But after trying for another 5 months our perseverance paid off. We got finally got our wish and found out that we could expect our second child. We were as elated as any parents could be. The anticipation and joy that comes with knowing that we were going to be parents again was indescribable.

At 16 weeks into the pregnancy, or just short of 4 months we elected to undergo the optional quad screen that was offered by our physician. While the screen is not required, we opted for the screen in order to prepare ourselves on the rare chance that there could be troubles with the pregnancy. The results of our quad screen came back that there was a potential problem. Our joy and elation quickly turned to fear and uncertainty. After an ensuing ultrasound at our local hospital that revealed some additional troubling indicators, we were referred to T the Maternal Fetal Medicine Specialists at The Nebraska Medical Center. The recommend tests were another ultrasound and an Amniocentesis At that time, the treating specialist immediately informed us that there were significant physical troubles with our baby.

The MD told us in no uncertain circumstances that we needed to prepare for a stillborn baby. We were informed that there was 0 %chance that our daughter would survive the pregnancy. It was 2 weeks before Christmas. A lot of tears and 24 hours later the chromosomal results were back. They confirmed what we already knew in our hearts but did not want to admit. We had already done the research on our own. We knew that the diagnosis was considered to be one with a 100% mortality rate. The official diagnosis was devastating. Our daughter Lily had Turners Syndrome (she had only one X chromosome), a large Cystic Hygroma (a cyst filled with lymphatic fluid that was on the back of her head and neck) and severe Hydrops (this is heart failure and her abdominal and thoracic cavities were filling with fluid). The recommendation was to terminate the pregnancy. With Christmas now less than 2 weeks away, my husband I were not ready to make the decision that lay ahead of us.

All of the doctors involved explained that they understood our troubles and recommended that we get through the holidays then set a date for termination of the pregnancy and stick to it. Their rational was to limit the possible physical complications I could experience and that it was important to set a time and do what we could to not drag out the inevitable. The future was written for us and the destination was known. Just to be sure I understood, he again repeated that there was no way that she could survive. He then told me that due to our babies condition he didn't think she would make it even 2 weeks. My heart was now shattered.

I am one of only two Certified Registered Nurse Anesthetists (CRNA) in a small hospital that needs continuous anesthesia coverage. I went back to work and took call over Christmas. My work surrounded me with pregnant mothers at the height of the human experience. While I was living at the other end of that spectrum.

I got through the New Year, but for the next weeks my husband and I were still not yet ready to proceed. This was an impossibly horrible decision. I loved feeling her kick and move like any other expectant mother might. However, the joy was quickly replaced with guilt and dread as I also hoped and prayed that I would not feel her. We hoped for something that a parent should never hope for. We hoped that our child would pass away. After all, if she stopped moving and passed away on her own then I would not have to take the actions I knew needed to be taken. I was emotionally torn in a way that no parent should experience. Termination of the pregnancy for medical reasons was well justified and highly recommended. The very intense emotions of a second time mother would not allow it.

To complicate the emotional toll of making an impossible choice, there was also the very real social stigma attached related to other peoples opinions related to terminating the pregnancy. I was made to feel guilty about my situation because of perception of a "choice" someone may have inferred. At the end of the day the necessary action that needed to be taken was recommended by my doctor. So why should I have to lie and worry about what any one else thought?

When I thought that I could potentially have to search for a different hospital and a different doctor or that I might be faced with seeking treatment from strangers who understood my horrible choice I could hardly bear the thought. If that were to happen, strangers would surround me at the most difficult moment of my life, not the family and friends that love and know me at my own hospital. To think that strangers would be delivering my baby because I might upset someone in my local hospital that was not even involved in my medical care dehumanized my very human pain. I was stripped of my humanity and quickly turned into a policy. I was devastated, crushed and felt very trapped. Eventually we resolved this problem but not with the honesty I would have wanted.

Then I would go to my weekly ultrasound. Every week I would fall in love with my daughter all over again. I loved watching her move and act like a healthy baby... but then I would feel horrible about the fact that she was now 22 weeks gestation. Her belly was the size of a 35-week fetus because of all of the fluid now surrounding her heart, her lungs, filling her body wall, making her arms, hands, head, feet, and face swell. As Lily got bigger so did I, I looked a lot further along than I was. I am smaller in physical stature, which only served to exaggerate my physical growth with the pregnancy. I was very noticeably pregnant. I felt uncomfortable going out in public for fear that someone would ask me about her or ask my due date. Those who knew looked at my belly before they looked at my face wondering when and how it was going to end. Words cannot describe how alone this made me feel.

Finally, my husband and I set our day. In the end, 4 days prior to my termination by labor and delivery I started having contractions and my sweet Lily did not kick me again. If I would have had to listen for a heartbeat or do an ultrasound to confirm that she was gone before proceeding, it would have been even more devastating. It was hard enough to make the decision that day to move forward. I couldn't have left the hospital to wait again. The labor was supplemented with

Melissa

6-2

extra medicine. Lily Ann was born still at 22 weeks and 4 days on January 25th at 3:30pm in Lexington, NE. Even though no one thought she would survive 2 weeks almost 6 weeks later part of our horrible journey was over.

That is my story, however I have a few comments to add regarding this proposed law. From my RN, BSN, BS in Biology, BA in Psychology and Masters in Nurse anesthesia, perspective. I spend my life trying to keep people from feeling pain.

1. Most women do not opt for the quad screen. This means that they would have no idea there was a major problem with their child until the standard 20 to 22 week detailed ultrasound.
2. If there is a such a stringent timeline families may be forced to make a decision before they have all of their results from chromosome studies and 2nd opinions. Parents should be as informed as they can be prior to this decision.
3. I perform Anesthesia on a daily basis. That being said during any D&E for termination most women are under general anesthesia. Our induction agents (the drugs that put you to sleep) cross the placenta, Our Narcotics (Pain medicines) cross the placenta, Our sedatives also cross the placenta. This is why we avoid any general anesthesia on pregnant women unless it is an emergency. So the argument that the fetus will feel the pain is not very valid.
4. During a L&D for termination mothers also get pain medicine and sedatives that will cross the placenta going to the baby. Even the narcotics used in epidurals and spinals cross the placenta. Again the pain would not be the issue.
5. Most of the time the baby is given an injection with a very small needle (no different than a vaccination shot) that stops their heart immediately. Then no pain is felt during any termination procedure.
6. There are some severe heart problems that would not be detected until the 20 week mark such as Hypoplastic Left heart disease. These infants can survive to term but then if they survive delivery need to have major heart surgery within days of birth, have IVs, shots, breathing tubes all with very little to no anesthesia and pain medicine because they simply cannot handle it. If they survive this surgery there will be 3 more surgeries and the likelihood they ever have any normal life outside of the hospital is slim to none without a heart transplant. This hardly ever has a happy ending. These babies are subjected to horrible pain almost continuously until eventually their bodies wear out waiting for a transplant.
7. Termination for Medical Reasons is a horrible choice no parent wants to make, but it should not be limited.

Melissa

6-3

My name is Christie Brooks. In 2003, I was a 30-something, stay-at-home mom with a 2-year-old daughter. I was 20 weeks into my planned pregnancy with my second daughter when a routine mid-pregnancy ultrasound revealed a possible problem. I was referred to a perinatologist's office where I was told that my unborn baby had a serious birth defect called congenital diaphragmatic hernia (CDH) which prevented her lungs from developing. A hole in her diaphragm allowed her stomach and intestines to migrate into her chest cavity. The extra organs in her chest caused her heart to be pushed over into her right armpit, her trachea and esophagus were pushed to the right of midline, and her lungs were virtually non-existent. I was told that no amount of in-utero surgery or treatment would create or grow lung tissue that wasn't already there. And while some babies born with this condition do survive, I was told that my baby's defect was one of the largest my perinatologist had ever seen. I was given the choice to carry her to term and likely watch her suffocate to death at birth, or to let her go peacefully from my womb, never having to endure endless surgeries, procedures, interventions, and medications.

After seeking out several more medical opinions, doing endless hours of medical research on the internet, speaking with parents who had faced the same defect, and having numerous round-the-clock discussions with my husband and other close family members, I made the agonizing decision to interrupt my pregnancy and say goodbye to my much-wanted little girl. I was induced into labor at almost 22 weeks at my local hospital, by my own OB/GYN. I was induced slowly, using IV drips, laminaria sticks, and prostaglandin suppositories. The labor lasted 16 hours and, with the exception of the final 30 minutes, was very well-controlled and peaceful.

It was important to me that my little girl not suffer, and it was important to me to be able to see her, to kiss her sweet face, and to say goodbye. She had been my constant companion for over five months. I needed the closure of being able to look into her face while I said goodbye. Although my preference was to be able to say goodbye to her while she was still alive, she passed sometime during the last hour of my labor. She was born still, and peaceful.

Over the years since her passing, I have often contemplated what life would have been like had I not been given the option to end her suffering early. The remaining four months of my pregnancy would have been tortuous--not only in having to deal with questions from others about the pregnancy and the baby's arrival, but in having to prepare my 2-year-old for the death of her little sister. Being forced to carry a doomed pregnancy to term would have devastated my family greatly, not only emotionally, but financially and spiritually as well.

It's been almost seven years since my termination. In that amount of time I have had ample opportunities to rethink my decision and my chosen path to end my pregnancy. I have absolutely no regrets, and I'm positive that if I were to be put in the same situation today I would choose the same path.

Please trust women to make these crucial decisions in the best interests of their families.

Christie Brooks

House Fed & State Affairs
Date: 2.17.11
Attachment 7

February 14, 2011

Hello,

My name is Susan and I am in opposition to HB 2218.

On May 11, 2009, at 20 weeks and 5 days gestation, my husband and I were told some devastating news. Our much wanted pregnancy of a baby girl named Keira was diagnosed with a severe Congenital Diaphragmatic Hernia. Half of her diaphragm was missing, allowing her abdominal contents to move into the chest cavity. Her stomach, intestines, spleen, liver, and appendix were in her chest. Both lungs and her heart were in the right thoracic cavity. Due to the displacement of these organs, her lungs were crushed and never formed properly. She did not have enough lung tissue to sustain life.

On May 19 we spared her a very short life of intense pain and suffering. She was born peacefully through labor and delivery. She never opened her eyes, she never even moved. She had no tubes or wires. I held her for two hours. She did not undergo several operations. She was never given paralytic drugs in an effort to prolong the inevitable. I absolutely, positively cannot imagine being forced to carry her to term. She would have struggled to breathe. She would have writhed around until she suffocated to death. She would have looked at me and wondered why I wasn't helping her. Either that or she would have been on heart and lung bypass until we decided to remove her from life support. And then she would have suffocated to death. Instead, she passed peacefully and unaware.

98% of babies are healthy. But there are thousands of problems that can unfortunately make a baby incompatible with life. For those of us who sadly, horrifically, and often time silently were on the wrong side of the healthy baby statistic, please acknowledge us. We loved our babies as much as any other parent. We did not want them to suffer for hours, days, weeks, or months after their birth, waiting for their inevitable death.

Thank You ,

Susan

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Date: 2.17.11

Attachment 8

My name is Michelle **and I am in opposition to** HB 2218

Here is my story:

On December 2, 2009, my husband and I went in for a routine 20 week ultrasound. At that time, I was 21 weeks pregnant. We were elated to find out we were having a boy that is, until the ultrasound technician abruptly stopped the screening and said "there's something abnormal about the baby's heart." On that day, we arrived at the doctor's office filled with hope and excitement and unfortunately, left with grave sadness and despair.

Our baby boy was missing his left heart ventricle and all the valves to his heart were connected only by one pulmonary valve. Additionally, our baby's stomach was on the wrong side and he was missing his spleen. The doctors didn't say he wouldn't survive. They would only go so far as to say that to save his life, barring no other complications, he would require open heart surgery upon birth, followed by minimally 2 more before the age of 1. Because his stomach was in the wrong spot and he was missing his spleen, they were fairly certain he suffered from another disorder too where the other organs develop abnormally. In that case, the open heart surgeries would not save his life. We were faced with an excruciating decision. We decided that the best interest of our son would be served by terminating the pregnancy so that he could be saved from enduring the painful road ahead.

The only thing worse than making the decision to terminate my pregnancy would be to watch our son suffer through 3 open heart surgeries before his first birthday. That he would only know life connected to tubes and machines, knowing he would ultimately lose his life at a tender age, was too painful for us to bear. As hard as it was to let him go, it was the humane thing to do. I did as much for my beloved labrador retriever several months earlier when she suffered from liver failure. I couldn't watch her suffer knowing she would never recover. As such, I made the hard decision to let her go. How is it any different for my child?

Being Catholic, this decision was wrought with the added guilt that I would be surely going straight to hell. I sought out the priest who married us and asked for his guidance prior to the termination. He gave me great comfort and assurance that our baby boy was in a better place and that our decision was based on our deep love for him as it was in his best interest.

On December 8, 2009, at nearly 22 weeks, my baby boy was born into heaven. I had a Dialation & Evacuation procedure with full anesthesia sedation. We had an autopsy performed that confirmed the doctors' diagnosis. Our baby suffered from Heterotaxy Syndrome and right atrial isomerism associated with asplenia.

I'm not going to say that I don't still struggle with our decision because I do. It seems like not a minute goes by that I don't think about him. We buried our baby on 12/15/09 with our priest saying a private blessing. I've been through a lot of hardship, but this was by far the hardest thing I've ever had to live through.

I want to be pregnant again. Not to replace our son, but to again experience the miracle of life. (We have a daughter who is 13 months). This experience has undoubtedly given me a greater appreciation for life and I am acutely aware of its fragility. I feel guilty asking God for another angel, as I already have been sent 2. So, I don't ask Him for another baby, I just hope that he bestows that blessing upon us again.

Michelle Michelle

9-2

16 February 2011

Kansas House Federal and State Affairs Committee
Chairman Steve Brunk
RE: HB 2218

Dear Chairman Brunk and Committee Members:

We arrived to a frantic message from the doctor. She sounded like a completely different woman from the one we met that morning. Once we connected, she told us that there was something wrong, and she wanted us to see a specialist. She only mentioned that the left side of our baby's heart was small. So we had an appointment set for the following Monday with a perinatologist.

Thanks to modern technology and the internet, you can take a small bit of info and open up all kinds of things. But searching "small left heart" lead us to only one thing... HLHS. Hypoplastic Left Heart Syndrome. After reading as much as we could, we were convinced that this is what we were facing, and spent the whole weekend crying and grieving. We just knew. By the time Monday came around, knowing what we were up against, we headed in for our level II and fetal echo. They confirmed what we had already guessed. The perinatologist wanted us to seek out one more opinion, but as far as she could see, the defect our daughter had was beyond the surgical procedures available to her. Yes, this time she let us know she was in fact a girl, and now we knew we had to make incomprehensible choices for our daughter, Miranda.

The next opinions came from specialists in Iowa City at the University of Iowa. We saw a neonatal cardiologist and a geneticist. The cardiologist confirmed everything we had heard up to this point, except she wanted a chance to do surgery. She talked of mortality rates and poor survival chances, and yet in the next breath she was telling us she wanted to perform open heart surgery on our daughter without any thought about what these two topics meant to each other. But the geneticist was the real surprise and gift to us. He looked at my amnio report and all of the other lab work done, and told us that there was nothing wrong with our genetics. It was just one of those things that happens. But the crucial thing he said to us was to go with our gut. And our gut was telling us that our daughter was not going to survive this. We also learned another important thing about teaching hospitals from him... they want the chance to practice, whether the results are good or bad. It was suggested to us that the gravity of Miranda's defect was being ignored. Regardless of her actual outcome, she could be a guinea pig of sorts for a surgeon in need of practice. And that was just not acceptable to us.

All of these appointments and second opinions didn't come overnight. It took us two full weeks to get through everything so that we could make an educated and well thought out decision for our child. If we had been restricted to 20 weeks, she would have been forced to go to term and die on hospice as an almost fully formed and functional baby. But she would never be, because the left side of her heart, the pump, was shriveled and deformed. And as her mother, I would have been forced to go through a full term C-

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section to deliver her, and risk the ability to have more children.

My husband and I made the decision for not only Miranda, but for all of us. We were a young family, and were so excited to be adding to it. This was no accident. Miranda was planned, wanted, and loved from day one. We did not choose for her to have HLHS, but faced with the diagnosis, we did what we thought was best for her. At 21 weeks gestation, I went into the hospital to be induced. After 4 days of induction and labor, Miranda was born. Yes, born. We had the chance to hold our sweet child, baptize her, and tell her how much we loved her. She lived only a few minutes, but those will always be some of the most profound moments of my life.

Her autopsy showed that she had another deformity that was not readily seen on the ultrasound. Her spleen was also very small and not properly formed. This convinced us that we made the right choice for our daughter! Many HLHS babies die not from the defect but from surgery related infections. So here we had a child that was considered a poor surgical candidate from the start, and her biggest defense was damaged too. I am thankful that we never put her through it.

We loved our little girl and feel we did the best we could for her. We celebrate her life and keep her in our hearts every day. Our boys will never get to know their sister, but they know she is a very important part of our family regardless of that fact. I guess that I would want anyone and everyone to know that this is not a decision taken lightly. It is never easy. And just because it is made does not mean that it is not made with love. We did this for our daughter because we loved her so much and didn't want for her to suffer. It would have been very selfish of us to put her through a longer life. Maybe we would have had a few days versus a few moments, but she would have suffered so much more during that time.

I appreciate the opportunity to tell our story. If there is any other info needed, please let me know.

Thanks,
Carmin Bullock
Grimes, IA

10-2

Hello:

My name is Melissa and I am in opposition to HB2218. I had a medical termination almost exactly two years ago. After my husband and I had been married for two years we decided we wanted to try to have a child. With great luck, we conceived quickly. I can't tell you how elated we both were. We had financially and emotionally planned for our child before we even knew that I was pregnant. I was excited at the prospect of being a stay at home mom.

We had an excellent OB/GYN who made sure I was on all of the pre-natal vitamins. I made sure I didn't eat anything I wasn't supposed to, such as certain kinds of fish, deli meat, etc. I tried to eat mostly organic foods.

When it was time for our routine check-up at 20 weeks we were so excited! We were going to find out the sex of our baby. I remember everything like it was just yesterday. My husband was at my side when the ultra sound tech was doing her job looking all over my tummy at the various parts of our precious child. All of a sudden, she excused herself & left the room abruptly. I remember that my husband didn't think anything of it. He didn't even seem concerned. I however, immediately knew there was an problem. I was confirmed when my doctor came back in with the ultrasound tech. My doctor started to explain to me that my precious, planned and much wanted child had a very horrible diagnosis. She said my child had an encephalocele. My baby's brain was growing outside the skull. There was a very minimal chance that my child would survive birth. If he/she did survive, most likely he/she would not be able to have any normal functions in life.

After that we had a whirlwind of various other doctor's appointments with the best specialists in my state. They all confirmed what my doctor had. My baby's prognosis was very bad. If he/she did survive to birth, most likely my child would die shortly after. I would have had to watch my child suffer to breath....to live.

Call it what you like....a medical termination, an abortion, an end to life. Nobody can judge what it is like to feel your loved child kick inside of you knowing that if you went through the whole pregnancy that he/she would suffer. Nobody can judge what it is like to make the hardest decision in a person's life to do the right thing....to do the motherly thing....to choose to end your baby's life so it didn't suffer a horrible death or live life as a complete vegetable. I love my child more than I can ever possibly say. I believe that I did what a mother should do, put her child first. I put my child before my own wishes. My son died peacefully in my womb two years ago this last January 31st. I love him, miss him, and think about him every day.

Melissa

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Attachment 11

Alesha E. Doan, PhD
Department of Political Science
University of Kansas
1541 Lilac Ln., Blake Hall 504
Lawrence, KS 66047

February 17, 2011

Members of the Committee on Federal and State Affairs,

Thank you for allowing my written testimony concerning House Bill No. 2218. I have several concerns with HB 2218, but I will limit my remarks to the two most troubling aspects of the bill. First, the bill is notable for the lack of credible scientific information contained in it. Second, the proposed bill would enact yet another policy that widens the scope of the state's regulation of the medical community and the private lives of families.

Much of the language included in HB 2218 regarding fetal pain conflicts with medical information that is supported by esteemed professional organizations such as the American College of Obstetricians and Gynecologists and the Royal College of Obstetricians and Gynecologists.

HB 2218 is also based on the inaccurate assumption that late term abortions (abortions obtained after 20 weeks of pregnancy) are commonly used as a means for irresponsible women to flippantly decide to terminate their pregnancy at any stage of their pregnancy. However, this assumption is unfounded and it is not supported by either statistical or scientific evidence. In fact, this characterization of a second trimester abortion is at odds with the reality of this type of abortion, which is uncommon, and typically results from a tragic and unforeseen medical diagnosis.

Although birth defects are relatively rare, affecting roughly 3% of births in the United States, they are the leading cause of infant mortality accounting for roughly 20% of all infant deaths. Advances in technology have improved doctors' ability to detect and diagnose fatal and severe birth defects like anencephaly, trisomy 13, and trisomy 18. However, there is no corollary cure or treatment available for these pregnancies.

Several of the most severe fetal abnormalities cannot be diagnosed until the second trimester of pregnancy. For the women and their families who are joyously anticipating the birth of their child, a lethal or severely abnormal prenatal diagnosis for their baby is devastating. These diagnoses often occur during the second trimester ultrasound, when many parents are hoping to find out the sex of their baby. Instead, the ultrasound becomes the beginning of a nightmare for families who are grief stricken and faced with limited options of how to proceed. Their decision is not arrived at lightly. Rather, women in consultation with their physicians, families, spiritual advisors, make their decision based on important factors particularly medical considerations. Late term abortion is one of the medical treatments that need to remain available in these complex and often dangerous pregnancies.

While late term abortions have become a popular topic in public political discourse, they are extremely rare; in fact, they account for less than 4/100ths of 1% of all abortions performed in the United States. This rate has remained nearly constant for more than 26 years.

The decision to pursue a late term abortion should remain within the purview of women, their doctors, and their families. The state should not curtail the limited medical options available to women, nor should it supplant the medical expertise of physicians. HB 2218 is an unnecessary intrusion into families' lives as they face such adversity.

Thank you for your time and consideration on this issue.

Regards,

Alesha E. Doan, PhD
Assistant Professor of Political Science

To: Members of the House Committee on Federal and State Affairs
From: Stephanie Imbesi
RE: HB 2218

On November 22, 2010, my husband and I went to a routine ultrasound appointment to learn whether we were expecting a baby girl or baby boy, due April 11, 2011. We were told during the course of the ultrasound that we were expecting a daughter, and I was elated. However, as soon as the perionatologist asked that we meet him across the hall in his office, I knew something was wrong. We learned that our daughter had a severe heart defect knows as hypoplastic left heart syndrome (HLHS). The doctor explained that this was a very serious diagnosis, which requires a series of 3 open heart surgeries, with the first to be performed very soon after birth. He explained that most people with this diagnosis opt to have the 3 open heart surgeries, commonly referred to as the Norwood surgeries, but explained that this is a palliative and not curative procedure, meaning that our daughter's heart would never be fixed and she was likely to require a heart transplant in early adulthood. He also talked briefly about the option to terminate, but he recommended that we have an amniocentesis and a fetal echocardiogram before deciding how to proceed with the pregnancy. Luckily, we had a personal connection with one of the top fetal cardiologists in the Philadelphia area, and she was able to schedule our echocardiogram for the same evening. Although we felt lucky to be seen so quickly, the news only got worse.

After performing the echocardiogram, the fetal cardiologist explained that our daughter had an intact atrial septum. This meant that there was no blood passing between the severely underdeveloped left side of our daughter's heart and the right side, which would eventually need to become the pumping chamber through the series of surgeries. Already, our daughter's blood vessels appeared black, meaning they were dying off. The fetal cardiologist explained to us that there was really no hope of survival for our daughter, despite advances in medicine. Our daughter was not expected to live through the series of 3 open heart surgeries that most children with HLHS have in the first few years of life. It was recommended that we strongly consider termination, or else deliver in a setting where only compassionate care be administered until our daughter passed away of natural causes, likely within hours of her birth. Faced with this devastating news, my husband and I made the heartbreaking choice to let our daughter go from this earth. Although this decision brought us severe pain, we did not want our daughter to be born blue and gasping for air with no hope of long-term survival.

The next day, Tuesday, November 23, we placed a call to Pennsylvania Hospital to schedule the procedure. Because it was Thanksgiving week, they agreed to fit us in for the two-day procedure beginning that very day. However, within an hour of the appointment, I received a telephone call from the hospital advising that because, and only because, I had Federal government insurance, the procedure would not be covered and I would need to pay over $7,000 up front. This was not a realistic option for me. I was able to schedule my procedure for Friday and Saturday, November 26 and 27, at a clinic in New Jersey. I still was required to pay up front and out of pocket, but the cost was closer to $2,000, which was a more realistic option for me. At 20 weeks, 5 days, I underwent a D&E to terminate a pregnancy that was planned, wanted and loved.

In my case, because my husband personally knew the cardiologist I needed to see for the second opinion, I was able to get an appointment immediately. Also, because my daughter's heart defect was determined to be fatal in and of itself, it was determined that there was no need for me to have an amniocentesis or other chromosomal tests prior to termination. I also was given an option to travel to another state to terminate at a clinic that was affordable for me. However, had these factors not all lined up the way they did, I very well could have been past 22 weeks of pregnancy when my termination took place. Although the choice I made was heart wrenching, and I still live with the grief of losing my much wanted daughter everyday, I cannot imagine how painful it would have been if I were waiting around for an appointment with a specialist, amniocentesis results, or funding, and missed my opportunity to do what I believed to be the most humane thing for my daughter simply because some state politicians decided that abortions would be banned after 22 weeks.

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Please realize that many fatal birth defects are not detected prior to the 20 week anatomy scan, which is often performed between 18 and 22 weeks of pregnancy. Banning abortions beyond 22 weeks may force a woman to carry a pregnancy to term even if she knows her child will die very soon after birth. But also, please realize that forcing a woman to act prior to 22 weeks could lead her to terminate a pregnancy prior to getting a second opinion or results of medical testing. No woman should be forced to make such a life altering decision without having all the available information. Thus, I ask you to vote against State Bill 2218--an irresponsible bill that would force women to make hasty and uninformed decisions.

2/16/11

TO: Kansas House Federal and State Affairs Committee

FR: Heather S Pew

RE: HB 2118 OPPONENT – WRITTEN ONLY

Ladies and Gentleman of the KS Legislature,

The story I am about to share is my reality. I implore you to listen with an open mind before deciding to pass legislation limiting access to abortion services at a pre-designated gestational cut off point.

In 2006, my husband and I became pregnant with our first. We were thrilled at how easily and quickly I was able to get pregnant, as I was 35 years of age. All of our early screenings and tests were going fine with no signs of complications and all was well except for raging morning sickness.

At 20 weeks (and visibly showing and feeling movement) we went for our level II ultrasound (based on my age I qualified) and were expecting no major news except for the sex of the baby. My life changed forever that day.

The ultrasound tech was quiet....too quiet...and sort of avoided answering questions. She stoically said that the doctor would be in to "go over everything." My heart dropped through the floor. Something wasnt ok. I just knew it. A mother always knows.
The baby was diagnosed with a significant and severe brain abnormality called Alobar holoprosencephaly, which is a fancy way of saying that the brain did not divide into the normal two hemispheres. As a result (in our case) in addition to massive brain damage, major system malfunctions, everything along the midline of the face is affected. Closely set and bulging eyes and a lack of properly formed nose.

If the earth could have stopped rotating on its axis, I was sure it had done so because time seemed to stand still. I wanted nothing more than for this to be a joke or a big mistake. But it wasn't.

We were told that
a) these cases are rare but devastating
b) the baby would more than likely die soon after birth IF I made it to term
c) that they had no real good explanation for why I had not miscarried earlier on
d) the vast majority of these cases are random, sporadic events but that there was a small body of research that had found 4 genes that had possible involvement but the percentages are extremely small (a total of like 10% of the total for all four combined).

We made the decision to have an amnio on the spot "just in case" and sent cells out to a lab in MD that specializes in genetic testing.

My heart was broken as was Davids. We were sick. We were referred for an immediate 2nd opinion and went over to another office and were given the same diagnosis and prognosis. We went from thinking we were going to find out the sex of our child to having to make the most difficult decision of our lives.

For us...it was an obvious but not easy decision to make. To keep our child from suffering what we felt would be unspeakable pain we made the decision to interrupt the pregnancy and to terminate. But doing so at 20-21 weeks is not a simple or painless process by any stretch of the imagination.

First of all u need to know that legally and technically we were at the legal limits in the state in which we live. We were given the option to be induced and deliver or to have a D & E. There was NO question in my mind that I could NOT handle being on a Labor & Delivery ward and delivering a baby who would die a painful death in my arms. Try to put yourself in my shoes for just a moment and answer that very same question because if you enact a 20 week gestational limit in the state of KS you are making that decision

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for another woman like me to have to further suffer.

We were referred to a doctor who specializes in 2nd trimester terminations for the D & E procedure. He was an angel of mercy in my book and always will be. It takes a very special person to do the work that he has committed his life to doing and still be caring and sensitive enough to hold my hand as I drifted off into anesthesia and to bring me fresh picked flowers from his garden in recovery.

It was a two day procedure...they insert dilation elements into tue cervix a day before the surgery. The pain of dilation that night was unspeakable ESP knowing what was happening. Dilating for a baby that would not be held. It was Halloween night and I laid upstairs in pain listening to trick or treaters come to the door.

After the surgery I would have to suffer with my body thinking I had birthed a baby...my milk came in and I had to bind my breasts with ace bandages for weeks to dry them up and minimize the blinding pain of doing so. My uterus twitched as it shrunk back down to normal size. My heart ached. Again, time stood still.

We found later found out that despite the incredibly small odds, we did have a genetic marker that was the culprit. My husband carries a sequencing error on ONE gene that accounts for ONE percent of the cases of AHPE. The kicker is that this is an autosomal dominant gene which means it is a 50/50 chance of recurrence every time. As u can see, our three year old daughter born in 2008 was a true leap of faith (which I often run short on), and a miracle baby.

I have always guarded and supported a womans right to choose, but this as you can see, this pushed me into another realm. I try to explain to those with opposing viewpoints that things are not as black and white as they may seem and that there is a world of gray that demands we protect the legal rights to choose what we choose, when we choose it. It's not just unwanted pregnancies, unmarried women, rape or incest victims, and careless teenagers who need these protections.

When the partial birth abortion ban was enacted my heart sunk, because this is really only one step away from the D & E procedure we had. It's a slippery slope when lawmakers start specifying which procedures are ok and which ones aren't. The only people and timelines that should be involved in this decision making process are a woman and her physician.

Legislators who insist on setting limits on access to abortions services don't want to see the world of gray, because it forces them to go to a place where they may have to reconsider their stand.

Many would say that what we did was "ok" because my life was in jeopardy. Let me be clear that never once was I told I was in jeopardy. Now had I insisted on trying to carry to term perhaps they would have said that but the decision we made was not based upon that.

I am passionate about sharing this story to those who want and need to hear it, because we cannot protect one woman's right to choose without protecting ALL women's right to choose. It just doesn't work that way in our system.

Please, do the right thing for the women of Kansas. Stay out of the business of mandating regulations on a woman's legal right to choose what is best for her and her family.

Thank you for your time

Sincerely,

Heather S. Pew

2/16/11

TO: Kansas House Committee on Federal and State Affairs

FR: Tracy Petruso

RE: HB 2218 OPPONENT – Written only

For the love of my daughter Elizabeth

My name is Tracy Petruso and I am in opposition of HB 2218.

I am the face of a late term abortion. I support a woman's right to interrupt a pregnancy for any reason but specifically am addressing the misconceptions of a late term abortion. I am Ivy League educated, an attorney and at the time was 38 who desperately wanted to add to my loving, supportive and stable family. This is my story.

In the fall of 2005 my husband and I were anxiously awaiting the arrival of our second child. After an early miscarriage and a naturally conceived quadruplet pregnancy that failed, we were excited about this pregnancy. Earlier in the pregnancy we had lost her twin. She was the survivor. Since there was an absorbing twin, it was our understanding we were unable to do first trimester screening testing like we had with our first daughter. On a whim, we decided to do the quad screening. Knowing that my results could be skewed because of my "advanced maternal age" we were nervous but prepared. We were not prepared to hear our chances for Trisomy 21 were 1 in 6. But I knew a lot of women with 1 in 3 chance odds who were holding perfectly healthy babies today. We decided on an amnio with preliminary Fish results indicating no chromosomal abnormalities. We flew to the East Coast to celebrate our great news with our family over Thanksgiving dinner. We had much to be thankful for.

Upon our return on a Tuesday night I got a call from my OB. He had been through the trials and tribulations with us. I wished him a happy thanksgiving and said "Oh yeah, I assume you're calling with the final test results. All okay?" He said, "No, actually they are not. The baby has Trisomy 18" I remember quietly saying, "Wow. That's so much worse." In my mind I heard the words and vaguely remembered the genetics counselor from years before saying I'd probably never met a trisomy 18 child because they didn't survive. I went into mechanical and clinical survival mode. My husband had been working late trying to get things finished before a trip we were taking in three days to Puerto Rico. We were taking our daughter as a special family trip before the new baby came and changed her world. I had to call him and tell him to come home; we weren't going to Puerto Rico.

We researched every single thing we could. Could it be a mistake? Could this be a mosaic? All came back with "not compatible with life." We also had limited time to make the decision. We were already at 20 weeks gestation. We learned that in the unlikely event our child survived the pregnancy, she would die shortly after- maybe hours or days. I understood it would also not be pretty. Those moments would be filled with tubes, machines, unnatural prolonging of pain and eventually she would struggle to breathe and would likely suffocate if her other organs most likely affected [heart lungs, kidney, brain] didn't fail first. Her body would betray her and she would die.

I truly didn't think I could watch my baby die. This baby was so longed for, so waited for. How could I have her knowing she'd be gone? I didn't think I could bear it. Self preservation. Then I looked at my eldest daughter, my heart, my reason for being and I knew. I couldn't have her watch her sister die. She was old enough to know sorrow and grief. She had a certain connection to my mother [whom she was named in honor of] and knew heartache but she was not old enough to witness and understand the painful death of her sister. This wasn't just my agony to endure – it was also hers. My instinct was no longer self preservation- it was fierce maternal protection of both the daughter I knew and the one I'd never know.

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My husband grappled with his faith but felt the most selfless thing to do was to let her go. As much as he wanted to hold her, will good health in her tiny body, he felt that was not merciful to her and to continue her suffering was selfish. We made the hardest decision we will hopefully ever make and scheduled the D&E. The dilation portion of the procedure was physically and emotionally very difficult but one we were willing to absorb to prevent her from suffering further. I was given something to relax me then had general anesthetic so I and the baby were completely sedated. I felt no physical pain during or after the procedure.

I was one of the lucky women able to have this procedure done at a reputable hospital in my home town. I recovered in the women's surgery unit, not maternity. When I was discharged I didn't wait in the area for my car with all the other mothers. They called me when my car was out front so I didn't have to see what I should have been taking home – a healthy child. I was treated with such kindness and dignity and only much later did I discover that I was the exception and not the rule.

It took me a long time to decide to have another child. I didn't want to replace Elizabeth and I knew I never could. In May, 2007 we added a healthy baby boy to our family. Each year on the day we let Elizabeth go both of my living children decorate a tree out front known to our family and everyone who knows us as "The Elizabeth Tree." She will forever be remembered and missed.

My name is Jill Meadows and I am a doctor of obstetrics and gynecology. I was on faculty at the University of Iowa for 11 years and currently serve as the medical director for Planned Parenthood of the Heartland.

As a doctor who specializes in obstetrics and gynecology and family planning there is one thing I know conclusively...there are many outcomes to pregnancy. People may believe that once a woman becomes pregnant that it will ultimately result in a normal live birth. It is important to understand this is not the case; miscarriage, fetal abnormalities, stillbirth, health concerns of the mother and yes, termination are among the many real outcomes of a pregnancy.

I am a Christian with faith-based principles. I do believe in heaven, that this life is temporary, and the most important thing is to follow our calling. My calling is to serve women and their families and to support them in their decisions regarding their reproductive health care. I have reflected, prayed, and studied the Bibles. Through this I have come to believe that life begins, not at conception, but when it becomes meaningful, when ensoulment is possible, when viability and taking breath is possible. The United States Supreme Court has recognized that there is no medical, religious or legal consensus as to when life begins. Our religious beliefs can differ, and we need to respect each other's religious beliefs.

I am also a doctor of medicine, which means that I am also guided by science. The current medical expert consensus regarding fetal pain is that the fetus is not sufficiently developed to experience pain until the third trimester. The issue of fetal viability is similarly complex and depends upon a multitude of factors including the underlying health of the fetus.

In my practice, I've seen a healthy woman in her early 30s become pregnant. She is very excited about her pregnancy! She undergoes the recommended prenatal screening tests including the integrated first and second trimester ultrasound and blood tests. These results are made available to her around 18 weeks of pregnancy (but for other patients it is not until 19-20 weeks). The tests show an increased risk of fetal anomalies. It is recommended she have a comprehensive fetal ultrasound examination and amniocentesis. The ultrasound shows a severe fetal heart defect. As a result a fetal ECHO is recommended, which is best done between 20-22 weeks last menstrual period(LMP). The amniocentesis is performed at 19 weeks and takes two weeks for the final results to confirm a variety of problems. So at 21 weeks LMP she receives devastating news about the poor prognosis of her fetus. She needs time to accept that there could be problems with her baby and discuss the situation with her spouse, family and faith leader. By the time a decision is reached as to what is the best decision for her current family, she is now 22 weeks LMP. For a woman who decides to terminate, it

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takes time to schedule the pregnancy termination. This law would not allow for her to have the benefit of any of these tests, nor the time to discuss the results with her family.

Examples of fetal genetic conditions which might occur: Trisomy 21(Down's syndrome), Trisomy 13 and Trisomy 18 (both conditions are incompatible with sustained life) as well as Monosomy X (**Turner's syndrome**) which can be associated with severe birth defects as large cystic hygromas and hydrops (overall fetal fluid overload). Other birth defects include **spina bifida** (some cases severe), **anencephaly** (no brain and incompatible with life), other major brain defects, and a multitude of **heart defects** (usually not detected until the level II ultrasound done at 18-20 weeks; with confirmatory fetal ECHO often done at 20-22 weeks).

House Bill 2218 would put a woman at a critical decision point in her life in harm's way. More importantly, fear of a negative outcome for the baby may have the unintended consequence of a woman rushing to an abortion decision rather than doing further testing out of fear of losing all control of the decision.

The current standard of viability already addresses the concerns of the proponents of this bill, and allows for the many different circumstances that a woman will face in making these heart wrenching decisions. As legislators called to serve our society for the good of all people in our society, I ask that you respectfully reject the premise of this bill and hold with the standard of viability as it currently exists under Kansas law.

Respectfully submitted,

Jill Meadows, MD