

MINUTES OF THE HOUSE FEDERAL AND STATE AFFAIRS COMMITTEE

The meeting was called to order by Chairman Arlen Siegfried at 1:30 P.M. on February 20, 2008, in Room 313-S of the Capitol.

All members were present except:

Richard Carlson:Excused
Nile Dillmore - Excused
Michael Peterson - Excused
Judy Morrison - Excused

Committee staff present:

Dennis Hodgins, Kansas Legislative Research Department
Mike Heim, Revisor of Statutes Office
Jason Long, Revisor of Statutes Office
Jeannie Dillon, Committee Assistant

Conferees:

Jason Long, Revisor of Statutes
Dr. Elizabeth Saadi
Tim Mosher
Lyndsey Stauble
Julie Burkhart

Others attending:

See attached list.

The Chair opened the meeting for bill introductions. A bill was requested by Representative Brunk that deals with fetal pain. Seconded by Brown, without objection, the bill was accepted.

The Chairman reopened the hearing on **HB 2615 - Abortion; late term abortion records; reporting and HB 2736 - Amendments to late-term abortion laws; reporting requirements; waiver of parental notice; civil remedies for violations of law.**

The Chairman opened the meeting to questioning of Jason Long, Revisor of Statutes, on **HB 2736.**

The Chairman asked Jason Long, if the content of **HB 2615** was duplicated in **HB 2736.** Mr. Long responded by saying that it was not exact. He explained that **HB 2615** was amending to require that the reports include a medical reason for the determination of gestational age and whether or not, at least for an abortion, what the statute standard is and that language is not implicated in **HB 2736.** The two bills would differ on that point.

Answering a question from a Committee member, Mr. Long explained the requirement of using an ultrasound in the bill. He stated that the requirement is that if the doctor who uses an ultrasound in the performance of an abortion shall inform the woman that she has a right to view the ultrasound. The doctor has to be already using the ultrasound equipment in the abortion for the requirement that he must offer the woman the right to view the ultrasound to be in effect.

HB 2615 would add language to KSA 65-6703 that would require that the medical reasons and medical basis for determining the gestational age and whether or not the fetus is viable be recorded and whether or not the fetus is viable as part of the determination the late term abortion is legal under the statutes.

Mr. Long told the Committee that he had omitted a point that was pertinent in his remarks on February 1, 2008, and told the Committee that he would be remiss if he did not bring it to their attention. **HB 2736** repeals KSA 65-6713. The statute eliminates the protection of doctors being sued for failure to obtain informed consent from the patient. Essentially if the woman feels that she was not properly informed prior to the abortion procedure, even if a doctor follows and does what he is supposed to do, she could still bring a lawsuit for damages. After answering all questions by the Committee, Mr. Long was thanked for his participation.

CONTINUATION SHEET

MINUTES OF THE House Federal and State Affairs Committee at 1:30 P.M. on February 20, 2008, in Room 313-S of the Capitol.

The Chair welcomed Elizabeth W. Saadi, PhD, Interim Director and Acting State Registrar for the Center for Health and Environmental Statistics. Dr. Saadi gave testimony on how **HB 2615** requires KDHE to alter information it collects for all abortions and expands the collection for late term procedures. She answered questions regarding data collection and stated that she expected that there would be additional information that would not be a simple code but a descriptive piece of information. When asked by a Committee member how the department currently complies with KSA 65-6703, Dr. Saadi stated that they collect the data the way it is being reported and leave it to others to interpret the data. She believed that they meet the letter of the law. ([Attachment 1](#))

After answering all questions from the Committee, Dr. Saadi was thanked for her testimony.

Tim Mosher came before the Committee as an opponent to give testimony about he and his wife's experience going through a late term abortion due to a genetic defect found by a comprehensive ultrasound. They met with a genetic counselor who discussed with them their options and clarified their daughter's condition which included Spina Bifida in its most severe level referred to as Myelomeningocele with pronounced hydrocephalus which is a build up of cerebra which is a buildup of fluid within the cranium. After answering questions from Committee members, Mr. Mosher was thanked for his testimony. ([Attachment 2](#))

Lyndsey Stauble, ProKanDo, gave testimony concerning Operation Rescue's website and a photo of her entering the clinic. She stated that sensationalism and "supposed" wrong-doing have no place in the law. ([Attachment 3](#))

ProKanDo was represented by Julie Burkhart who is an opponent of **HB 2736**. Ms. Burkhart thinks that while these bills speak in abstracts, the people affected have to live with the very real and very difficult ramifications. She states that most of us have never been faced with the painful and difficult decisions faced by uncounted families every year. She concluded by saying that each family simply wants to make the best decisions for them at that moment in time. ([Attachment 4](#))

Ms. Burkhart supplied a copy of a DVD which was distributed to the Committee. Ms. Burkhart explained that the DVD was of the experience of a couple who had to a very difficult decision to make regarding their unborn child. Mariam was 27 weeks along in her pregnancy with a nonviable fetus. (On file in room 161-W) The Chairman encouraged the Committee members to view the DVD.

Chairman Siegfried asked Ms. Burkhart if she was also in opposition of **HB 2615**. Ms. Burkhart answered that she was only testifying against **HB 2736**. After answering questions from the Committee members, Ms. Burkhart was thanked for her testimony.

A copy of the Kansas Department of Health Report of Induced Termination of Pregnancy form that was asked to be submitted by the Committee was obtained and distributed. ([Attachment 5](#))

Chairman Siegfried closed the hearing on **HB 2615** and **HB 2736**. The meeting was adjourned.

Written Testimony was submitted by:

Holly Weatherford, Planned Parenthood of Kansas and Mid-Kansas ([Attachment 6](#))

Pedro Luis Irogonegaray, Attorney at Law ([Attachment 7](#))



Kathleen Sebelius, Governor
Roderick L. Bremby, Secretary

DEPARTMENT OF HEALTH
AND ENVIRONMENT

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Division of Health

House Bill 2615

**Presented To
House Federal and State Affairs**

**Presented by Elizabeth W. Saadi, Ph.D.
Interim Director and Acting State Registrar
Center for Health and Environmental Statistics**

February 20, 2008

Chairman Siegfried and members of the Committee, I am pleased to appear before you today to discuss the impact HB 2615 will have on the KDHE abortion reporting function.

HB 2615 requires KDHE to alter information it collects for all abortions (*medical reasons for determination of gestational age of the fetus*) and expands the collection for late term procedures (*medical basis for determining viability and specific medical or clinical diagnosis*). Regulations will be developed regarding how the data will be collected.

Current expectations are that the impact to the abortion reporting program is a) modification of the actual reporting form b) revisions to the electronic on-line abortion reporting system to accommodate screen and database changes c) development of reporting and record-keeping regulations and d) identification and/or hiring of medical professionals with expertise in medical records to consult in developing the required regulations.

In addition to functional changes for this system, KDHE will reassess the status of abortion reporting reports with regard to the specific medical diagnosis data. This may require additional legal consideration as to whether these reports will become a medical record if specific medical diagnoses are collected.

Thank you for the opportunity to appear before the Federal and State Affairs committee today. I will now stand for questions.

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House Fed and State Committee
February 20, 2008

Attachment /

Testimony of Timothy Mosher and Dawn Mosher

My name is Tim Mosher. I am 41 years old and reside outside St. Louis Missouri. My family of origin consists of my Mother, Father, two Sisters and one Brother. The majority of my family has been and currently is in the field of education, ranging from my youngest sister who is a science teacher in North Carolina to my Father who obtained his PHD in primary and secondary education and recently retired from the educational system as a Head Principal of a high school in Tempe Arizona.

My own family consists of my Wife Dawn, my oldest Son Justin who is 18, my Son Brenden who is 5 and my youngest child Ryan who is 1. My family means the world to me and I consider myself a devoted person who holds a deep capacity to love.

I am a career Firefighter and Emergency Medical Technician and have been blessed to be a part of the fire service for 22 years of my life. I have had so many wonderful experiences in the fire service and have been witness to so many miracles in life. These range from performing CPR on a 50 year old man whom suffered a cardiac arrest allowing him a second chance to live to assisting in the birth of a child at home since the child could not wait to be delivered at a hospital.

The other side of the fire service that has left a lasting impression in my heart and mind is the negative side to the fire service: The death of loved ones by a terminal illness, the various ways in which people have committed suicide, placing people in body bags as a result of motor vehicle crashes, to seeing someone's body burned to death from a house fire. I realized a long time ago that my perception of the fire service, pre involvement, has changed dramatically since becoming a firefighter. It is hard for anyone to really understand both the positive and negative aspects to the fire service unless they themselves walk a mile in my fire boots. None the less, the fire service represents so much about how life really works as life away from the fire service has its own positive and negative aspects.

I know up until this point I have not shared with you that in addition to my Sons I also have a daughter. Her name is Karalyn Grace Mosher and she is here with me right now, not physically but spiritually. I would like to share a photo along with her hand prints. This photo was taken in-utero at 14 weeks of fetal development.

To complete our family unit Dawn and I wanted one last child. We both hoped and dreamed for a baby girl and with no prior pregnancy complications to consider we conceived a child in January 2004. This last pregnancy was considered a textbook pregnancy. That was until May of 2004.

We went to our Doctor on May 18 for our comprehensive ultrasound and after the completion of that ultrasound we discovered our hopes and dreams had come true. Our child was a baby girl. All of us were on cloud 9 until our doctor came in and discussed a possible complication. He used the words Spina Bifida. I sat there so helpless and watched my wife go from total elation to total sorrow all in the matter of 30 minutes.

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Our world stopped turning and began spinning in all different directions. Questions needed to be raised and answers needed to be found to what was going on with our baby girl. In essence, we needed to make sense of something that made no sense. We needed clarity, as we soon could see that this textbook pregnancy was far from textbook.

We met with a genetic counselor at a prominent St Louis hospital. She discussed what preliminarily was seen on our ultrasound. She discussed what our options were for purposes of clarifying our Daughter's condition. We started with an Amniocentesis in conjunction with ultrasounds via a Perinatal Specialist who specializes in fetal abnormalities. The amnio results confirmed our Daughter's Spina Bifida and the comprehensive ultrasound confirmed our Daughter's true condition. Karalyn Grace was diagnosed with the most severe level of Spina Bifida referred to as Myelomeningocele with pronounced hydrocephalus which is the build up of cerebral spinal fluid within the cranium.

The severity of this fluid build up caused our Daughter's brain not to properly develop. In fact, the pressure build up was so severe that her brain sat at the base of the cranial opening and her skull was shaped like a lemon.

The severity of our Daughter's condition occurred the moment her neural tube failed to close properly which was at approximately four weeks into her fetal development. Due to this, all treatable options became no options at all. The damage was beyond repair.

Dawn and I spent hours researching our options, praying over our options and analyzing All the pieces of our life puzzle. We did so out of moral and ethical obligations but also because we wanted to base any and all decisions on real and proper information not solely upon opinion or feelings. This process was ongoing and filled with much pain and sorrow. Many tears were shed not just by Dawn and I but also our family and close personal friends.

We relied heavily upon our personal faith and beliefs in the God of our understanding to show us the way and help us make the best possible decision for our Daughter. A decision based on Love, Respect, Dignity and Devotion. Not based on hatred or resentment for how our life cards had been dealt to us to manage.

Towards the end of this process our puzzle pieces started painting a picture for us to see. Once this picture became clear one strong fact stood out. That our Daughter while in-utero was secure in her environment but once out in the world under the environmental pressures, her body would have began downward mobility and her life would have come to a final conclusion. In my wife and my eyes the harsh reality revolved around suffering and posed quality of life questions for us to answer.

We looked hard within our hearts and asked one simple yet complicated question. What would we want for ourselves if we were faced with a quality of life surrounded around pain and suffering with a conclusion that leads to death? The answer we both offered was unanimous. We would not want to live if our quality of life was filled with pain and

suffering. The decision was clear and powerful and again filled with much hurt and pain to endure.

Dawn and I met with our genetic counselor and confided in her our decision to end our Daughters life. She offered us options for doctors and facilities both in and out of the state of Missouri. This was the first time Dawn and I ever heard of Dr. George Tiller and Women's Healthcare Services located in Wichita Kansas.

Dawn and I knew what qualities we needed to have within the care of a doctor and their staff that revolved around such a spiritual, emotional and physical aspects to our situation. We called Women's Healthcare Services and through questions discussed and information provided to us, Dawn and I felt that Doctor Tiller and his staff were going to offer us the support and services we needed to get through such a difficult decision.

On June 1st 2004 Dawn and I flew to Wichita and on June 2nd met in person Dr. Tiller and his staff. If there is any truth in the fact that first impressions are lasting impressions, then Dawn and my first impressions of Dr tiller and his staff was compassion, commitment, concern, dignity, kindness, love and respect.

So much hurt and pain. So many tears that no words I say to all of you will really do justice to what my wife and I had to walk through before June 3rd and after. I doubt any of you can fully understand that as a firefighter I show up to assist someone who is in need of help for a better positive outcome. Yet here I was personally as a spouse and father faced with no power to really change the outcome. I felt helpless and had to, with my own daughter, let go and let God take over.

On June 2, 2004 with Dr Tiller and his staff standing witness, our Daughter was baptized by Reverend Avelino T. Baguyos. Standing by Dawn's side with my left hand on her belly and my right hand embracing hers, tears of sorrow filled our eyes with a room filled with heavy hearts it was time to let go. Our Daughter, Karalyn Grace Mosher, passed away on June 2, 2004 at approximately 2:45 pm. In that moment a piece of my soul and a piece of Dawn's soul passed away along with our Daughters.

As a lasting impression of Dr. Tiller and his staff, Dawn and I can look back in reflection and feel Respect, Love and Honor for what was otherwise such a powerfully horrible life altering experience. It is the opinion of my wife Dawn and I that the entire state of Kansas should be proud of Dr. Tiller and his staff for offering so much understanding and compassion through the services he provides.

Dawn and I never thought we would ever be included in such statistics like Neural Tube Defects or having to go through a late term abortion. But then again who said that life is fair or that Dawn and I, along with any of you would ever be exempt from becoming a statistic for others to dissect, criticize or offer misunderstanding?

I have lost the ability to be naive. I have realized that I should hold off on my opinions of others and not cast stones unless I myself can or have to walk a mile in someone else's painful shoes.

Picking up the pieces and moving forward has been just as difficult but life has gone on, it has to.

Dawn and I conceived Karalyn for many loving reasons. One was to bring a sibling close in age to our Son Brenden. After time to heal, we decided to try one last time to bring life into this world. This time we, in conjunction with a general OB/GYN, consulted with a perinatal specialist. During our meeting with this specialist we reviewed our history of Karalyn and what we had decided ultimately to do. He disclosed to us that he and his wife, if faced with what we were faced with, would have chosen the exact same thing. A sense of warmth came over me that others, particularly some from within the medical community, could understand and empathize with my story.

I have realized that life is not just black or white but grey as well. The toughest lesson I have had to learn through my pain is that I ultimately do not have the right to decide for another human being how they themselves handle the black or white issues or what within gray needs to become black and white based upon my own lifestyle or belief system. I spent much of my life looking at things in terms of black and white, especially when it came to Pro Life versus Pro Choice issues. Through my experience I have realized that there is grey within this issue that needs to be understood and nurtured. Though much of my life represents Pro Life, I understand the power and freedom of choice and will always be in support of this freedom.

I pose these open ended questions to each of you individually to answer privately for yourselves:

1. If you yourself were placed in a medical position that revolved around quality of life issues and medically there was not hope for you to ever have a healthy quality of life, what would you want for yourself?
2. If you find yourself in this position would you really want other people, including a political body, to choose for you or your spouse what your quality of life should be or to make it more difficult for you or your spouse to choose for yourselves?

If your answer is no, then why would you want to either take that choice away or make it more difficult to choose for another human being?

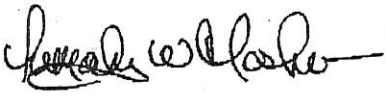

Dawn and I both felt that the best way to honor our Daughters death would be through the gift of life. With much courage and strength and a lot of faith we went on to conceive another child despite the fact that the statistics were not in our favor.

This last photo represents some our miracles in life despite the heartache and our times of despair. Our last son Ryan Timothy Mosher was born on January 15, 2007. Our red headed blue eyed boy has all 10 fingers and 10 toes and is a completely healthy boy.

Ryan Timothy was born 1 day early and arrived on someone else's important birthday which we celebrate nationally each year. Ryan was born on Martin Luther King's birthday. The irony is that Martin Luther King left behind a message of Freedom just as my story too represents freedom.

From one public servant to another, thank you for allowing me just for today to share my story. Thank you for the chance to hear my voice and the voices of all others that have had the unfortunate opportunity to walk a mile in my shoes.

We certify that this is our testimony this 17th day of February 2008

Timothy Mosher
Dawn Mosher

Enclosures



Professionals & Researchers

Quick Reference and Fact Sheets

Spina Bifida

Spina bifida is the most common of a group of birth defects called neural tube defects (NTDs). The neural tube is the embryonic structure that develops into the brain and spinal cord. Often called open spine, spina bifida affects the backbone and, sometimes, the spinal cord. It is among the most common severe birth defects in the United States, affecting 1,500 to 2,000 babies (one in every 2,000 live births) each year. Spina bifida and other NTDs occur more frequently among Hispanics and whites of European extraction and, less commonly, among Ashkenazi Jews, most Asian ethnic groups and African-Americans.

How does spina bifida affect a child?

In the embryo, there is a tiny ribbon of tissue that folds inward to form a tube. This structure, called the neural tube, forms by the 28th day after conception. When this process goes awry and the neural tube does not close completely, defects in the spinal cord and in the vertebrae (small bones of the spine) can result. There are three forms of spina bifida:

- **Occulta.** In this usually symptomless form, there is a small defect or gap in one or more of the vertebrae of the spine. The spinal cord and nerves usually are normal, and most affected individuals have no problems.
- **Meningocele.** In this rarest form, a cyst or lump consisting of membranes surrounding the spinal cord pokes through the open part of the spine. The cyst, which can vary in size, can be removed by surgery, allowing for normal development.
- **Myelomeningocele.** In this most severe form, the cyst holds both the membranes surrounding the spinal canal and nerve roots of the spinal cord and, often, the cord itself. Or there may be no cyst, but only a fully exposed section of the spinal cord and nerves. Spinal fluid may leak out. Affected babies are at high risk of infection until the back is closed surgically, although antibiotic treatment may offer temporary protection. In spite of surgery, some degree of leg paralysis and bladder and bowel control problems remain.

The severity of paralysis is largely determined by the spinal nerves involved. In general, the higher the cyst on the back, the more severe the paralysis. About 80 percent of spina bifida cysts are in the lower back's lumbar and sacral regions.

What causes spina bifida?

Spina bifida usually is an isolated birth defect. Although scientists believe that genetic and environmental factors may act together to cause this and other NTDs, 95 percent of babies with spina bifida and other NTDs are born to parents with no family history of these disorders. While spina bifida appears to run in certain families, it does not follow any particular pattern of inheritance. If one child has spina bifida, the risk of recurrence in any subsequent pregnancy is greatly increased, to about one in 40. If there are two affected children, the risk in any subsequent pregnancy is about one in 20. Spina bifida also can occur as part of a syndrome with other birth defects. Here, inheritance patterns may differ from those of isolated spina bifida.

Women with certain chronic health problems, including diabetes and seizure disorders (treated with certain anticonvulsant medications), have an increased risk (approximately 1/100) of having a baby with spina bifida.

How is spina bifida treated?

Spina bifida occulta usually requires no treatment. Meningocele, which does not involve the spinal cord, can be repaired surgically, usually with no paralysis. Most children with meningocele develop normally. However, affected children should be evaluated for hydrocephalus and bladder problems so they can be treated promptly. A baby with the most

severe form of spina bifida, myelomeningocele, usually requires surgery within 24 to 48 hours after birth. Doctors surgically tuck exposed nerves and spinal cord back inside the spinal canal and cover them with muscle and skin. Prompt surgery helps prevent additional nerve damage from infection or trauma. However, nerve damage that already has occurred cannot be reversed and limb paralysis and bladder and bowel problems usually remain.

As soon after surgery as possible, a physical therapist teaches parents how to exercise their baby's legs and feet to prepare for walking with leg braces and crutches. Studies show that about 70 percent of affected children can walk with or without these devices, although many children will require a wheelchair.

About 90 percent of children with the most severe form of spina bifida develop hydrocephalus, or fluid on the brain. When the cerebrospinal fluid, which cushions and protects the brain and spinal cord, is unable to drain normally, fluid collects in and around the brain, causing the head to be enlarged. Without treatment, mental retardation and other neurologic damage may result.

If the child develops hydrocephalus, fluid can be drained from the brain through surgical placement of a special tube called a shunt. The shunt runs under the skin into the chest or abdomen, and the fluid passes harmlessly into the child's body.

Most children with severe spina bifida have a tethered spinal cord, meaning that the spinal cord does not slide up and down with movement as it should, because it is held in place by surrounding tissue. While most children have no symptoms from this, some suffer progressive loss of function in their legs, and a few develop scoliosis (curvature of the spine). If the spinal cord is surgically untethered soon after these symptoms begin, a child should return to his or her usual level of functioning.

Other chronic complications associated with severe spina bifida include obesity, gut and urinary tract disorders, psychological and sexual issues, and learning disabilities.

According to the Spina Bifida Association of America (SBAA), between 18 and 73 percent of children with spina bifida are allergic to latex (natural rubber), possibly due to intense exposure during surgeries and medical procedures. Symptoms may include watery eyes, wheezing, hives, rash, and even life-threatening anaphylactic reactions. Doctors should use only nonlatex gloves and equipment during any procedures on individuals with spina bifida. Affected individuals and their families should avoid latex items often found in the home and community, such as baby bottle nipples, pacifiers and balloons (a list is available from the SBAA).

With treatment, children with spina bifida usually can become active individuals. At least 70 percent of children with spina bifida have normal intelligence, although some children do have learning problems. Most affected women can have children, but such pregnancies are considered "high risk," as the risk of having a baby with spina bifida is about 1 in 100.

Can spina bifida be prevented?

Studies show that, if all women in the United States took enough of the B vitamin folic acid every day before and during early pregnancy, up to 70 percent of neural tube defects (including spina bifida) could be prevented. The key is having enough folic acid in the system before pregnancy and during the earliest weeks of pregnancy, before the neural structures close. The March of Dimes recommends that women take a multivitamin containing 400 micrograms of folic acid daily, and eat a healthy diet including foods rich in folic acid. This is the most reliable way of ensuring that a woman gets all the folic acid she needs.

Foods that contain folate (natural folic acid) include: orange juice, other citrus fruits and juices, leafy green vegetables, beans and whole-grain products. Multivitamins, fortified breakfast cereals, and enriched grain products contain a synthetic form of folic acid that is more easily absorbed by the body than the natural form. It is estimated that about half of food folate is absorbed by the body, while most (about 85 percent) of folic acid in fortified foods and virtually all (100 percent) of the folic acid in a vitamin supplement are absorbed. This is why the March of Dimes, Centers for Disease Control and Prevention (CDC), and Institute of Medicine recommend that women who could become pregnant consume 400 micrograms a day of the synthetic form. However, women should not take more than 1,000 micrograms (or 1 milligram) without their doctor's advice.

Women who already have had a baby with spina bifida or another NTD, as well as women who have spina bifida, diabetes or seizure disorders, should consult their health care providers before another pregnancy about the amount of folic acid to take. Studies have shown that taking a larger dose of folic acid daily (4 milligrams), beginning at least one month before pregnancy and in the first trimester of pregnancy, reduces the risk of having another affected pregnancy by about 70 percent.

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Can spina bifida be detected prenatally?

Spina bifida often can be detected before birth using two or more tests. Most health care providers now routinely offer pregnant women a blood test called the maternal serum alpha-fetoprotein (MSAFP) screening test (part of the "triple screen"). This test detects pregnancies at higher-than-average risk of spina bifida and other NTDs, as well as certain other birth defects, including Down syndrome.

If a woman has a high MSAFP test result not caused by factors such as a miscalculation of fetal age, her health care provider probably will recommend two additional tests that are accurate in detecting severe spina bifida. These are a detailed ultrasound examination of the fetal spine, and amniocentesis to measure levels of alpha fetoprotein (AFP) in amniotic fluid.

What are the benefits of detecting spina bifida before birth?

When spina bifida is diagnosed before birth, health care professionals can provide parents with information and support. They can plan for delivery in a specially equipped medical center so that the baby can have any necessary surgery or treatment soon after birth.

In 1991, March of Dimes grantee David B. Shurtleff, MD, and others at the University of Washington in Seattle, found that cesarean delivery prior to the onset of labor can reduce the severity of paralysis in babies with spina bifida. If a baby is prenatally diagnosed with spina bifida, parents can discuss the possibility of a planned cesarean delivery with their doctors.

More than 100 babies have undergone experimental prenatal surgery to repair severe spina bifida before birth. A 1995 study by March of Dimes grantee N. Scott Adzick, MD, Children's Hospital of Philadelphia, suggests that chemical and physical trauma to the exposed spinal nerve tissue in the womb contributes to paralysis after birth, and that early repair may help prevent paralysis and other complications. To date, this procedure is being performed at only two medical centers, Children's Hospital of Philadelphia and Vanderbilt University Medical Center in Nashville, Tenn. Preliminary results appear promising: fewer babies who have had surgery require shunts to drain fluid from their brains. However, it is too soon to know how well most of these babies will walk, and there is a high risk that the procedure can induce preterm labor.

Is the March of Dimes conducting research on spina bifida?

March of Dimes grantees are searching for genes that may cause a predisposition to spina bifida and other NTDs and for improved treatments. One of our grantees has recently identified a mutation in a gene that helps to regulate how the body processes folic acid. Since maternal folic acid deficiency can lead to a baby with spina bifida, this mutant gene may increase the risk of having a child with spina bifida.

March of Dimes grantees also are seeking to improve the treatment of children with spina bifida through improved surgical approaches. One grantee is developing programs to prevent behavior and adjustment problems during adolescence in children with spina bifida. Another is studying how specific memory deficits may play a role in academic difficulties in some children with spina bifida. The March of Dimes also heads the National Council on Folic Acid, an alliance of organizations working to prevent NTDs.

What resources are available for families affected by spina bifida?

Genetic counselors can help families with questions about the chances of having affected children, and can explain prenatal testing for NTDs like spina bifida. The SBAA, with chapters nationwide, also can provide information and a newsletter.

Spina Bifida Association of America
4590 MacArthur Boulevard, NW., Suite 250
Washington, DC 20007-4226
Telephone: (202) 944-3285 or (800) 621-3141

Addendum: New Fetal Surgery Trial

The most severe form of spina bifida (open spine) is myelomeningocele (see above). It occurs in one out of every 1,000 pregnancies, and nearly always requires surgery as soon as possible after birth, usually within the first day or two. Based on the hope that the earlier the surgical repair could be done, the better would be the chance of an improved outcome for the baby, pioneer surgeons in recent years developed an experimental technique for performing the surgery prenatally, somewhere between the 19th and 25th weeks of pregnancy. These efforts at fetal surgery sometimes seem to result in a beneficial outcome for some of the serious complications of myelomeningocele. However, as yet, there are insufficient data to know if the results of fetal surgery were worth the added risk. Potential complications include greatly increased chances of premature delivery for the baby, with its own risks to the child. There are also risks for the mother, who has to undergo otherwise unnecessary surgery, with the risk of suffering long-term adverse effects, in order to allow access to the fetus.

Recently the National Institute of Child Health and Human Development (NICHD), a part of

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the National Institutes of Health (NIH), approved support of a controlled clinical trial to test whether prenatal surgery or postnatal surgery is the better way to "manage" (treat) myelomeningocele. Hence, this research project is called the Management of Myelomeningocele Study (or MOMS). It will entail the enrollment for surgery of 200 women whose fetuses have been diagnosed as having myelomeningocele. Half of these babies will undergo surgery during gestation, while the other half will do so shortly after birth. The outcomes for the children and their mothers will be assessed in an effort to determine whether carrying out the procedure prenatally leads to an overall improvement for these children—with acceptable risks. The surgery will be carried out at three major university medical centers—The Children's Hospital of Philadelphia (affiliated with the University of Pennsylvania), the University of California at San Francisco, or Vanderbilt University Medical Center in Nashville—while the data will be coordinated at a fourth, George Washington University in Washington, D.C.

The March of Dimes supported earlier research to develop techniques for fetal surgery. In the case of spina bifida (and especially myelomeningocele), the March of Dimes applauds continuing attempts to better manage and treat this birth defect. The March of Dimes has no role in this new MOMS project, neither endorsing, supporting, or funding the research initiative.

For a balanced discussion of the ethical considerations involved in fetal therapy (including fetal surgery), please see the policy statement issued by the American Academy of Pediatrics.

En Español: Click here to view this fact sheet in Spanish.

To order multiple copies of this fact sheet:
Call: (800)-367-6630

References

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09-264-00 3/01

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2-9



ST. JOHN'S MERCY
MEDICAL CENTER Genetic Counseling Consultation

July 26, 2004

Dawn and Tim Mosher
3609 Arlington Dr.
St. Charles, MO 63303

Dear Dawn and Tim,

We know the past few months have been difficult for both you and we hope this letter finds you both well. This letter is a summary of the information we discussed regarding the diagnosis of spina bifida in your recent pregnancy. We encourage you to keep this letter with your medical records, as you may need it for future reference.

You were seen for genetic counseling on May 21, 2004 because your ultrasound at Dr. Herrmann's office identified your fetus as having spina bifida. This was confirmed by ultrasound at the Perinatal Center on May 24, 2004 and you elected to have an amniocentesis at that time, which was performed by Dr. Sue Moore.

The amniocentesis results indicate that your fetus had the normal number of chromosomes (46), but the AFP was elevated and the acetylcholinesterase was present, which is consistent with spina bifida. After careful consideration, you chose not to continue the pregnancy.

Neural tube defects are a group of birth defects of the spine, where the spine (neural tube) does not develop correctly and the spine and neural tissues are exposed to amniotic fluid. This spine defect occurs approximately 4 weeks after conception. Approximately 1 in 1000 children are born with some type of neural tube defect. With the more severe types, the children do not usually survive.

Usually, neural tube defects are sporadic and not inherited in families. However, approximately 5% of children with a neural tube defect will have a positive family history. Since you have now had one fetus with spina bifida, there is a 3-5% chance with each future pregnancy for the baby to also have a neural tube defect. We recommend that Dawn take 4mg of folic acid daily for 2-3 months prior to conception and during the first trimester with each future pregnancy. Studies have shown that this decreases the recurrence risk to approximately 1%.

With your next pregnancy, we expect that you will be anxious. Feel free to contact Noelle at 314-569-6884 if you need to talk. We are very optimistic that you will have a healthy child and we wish both of you the very best.

Sincerely,

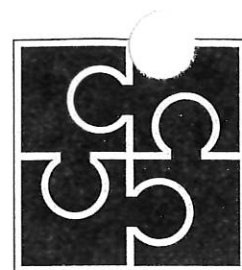
Noelle R. Agan, MS, CGC
Certified Genetic Counselor

Sue D. Moore, MD, FACOG
Specialist, Maternal Fetal Medicine

cc: Joseph Herrmann, MD

2-10

Good afternoon ladies and gentlemen of the Committee. Hello, my name is Lyndsay Stauble. I want to start by thanking you for your attention to this important issue. I'll also ask you to forgive me for my informal attire; anyone who knows me would tell you that I don't make it a habit to come to the Capitol in jeans. But I am dressed this way to illustrate a point. My photo has been posted on Operation Rescue's website and presented to a grand jury as "proof" of an illegal late term abortion. The photo was taken without my knowledge or consent on Nov. 13th 2007, when I was about 19 weeks pregnant. I'm wearing basically the same outfit I was that day with the exception of a different shirt since I can no longer fit into the one pictured. Obviously, I did not have a late term or any other kind of abortion. I'm due in eight weeks and very grateful to say that this baby and I both are healthy. I go into the clinic with some regularity so I guess I should not be shocked to see my picture online. But I was both surprised and disturbed. I was even more disturbed to find that my picture was being presented as evidence which is obviously quite flawed. A picture may be worth a thousand words, but in this particular case, it's not even worth that. I'm bringing this to your attention for only one reason: a reality check. Often, proponents of abortion reform will present all kinds of "evidence" and "proof" of supposed wrong-doing. I would ask that as you look at what you've been presented, please take it with a grain of salt and remember that sensationalism and bluster have no place in the law. Thank you again, I'll be happy to stand for any questions.



ProKanDo

www.prokando.org

Julie Burkhart
Chair

Lyndsay Stauble
Treasurer

House Fed and State Committee
February 20, 2008

Attachment **3**



1. Nov. 13, 2007

3-2

Ladies and gentlemen of the committee, I want to thank you for allowing me to speak here today regarding HB 2736. We've heard a great deal of testimony about a very difficult and sensitive subject.

I was raised with the principle that honesty is always the best policy. So I'm going to be honest about this bill and what it represents. HB 2736 is about restricting a woman's right to safe and legal reproductive health care. This bill is about restricting that right because outside observers find it to be disagreeable according to their own moral code.

There's not a person in this room who doesn't have a strong belief on this subject. Everyone is entitled to his or her opinion. I came here knowing that mine would neither be the most easily accepted, nor the most popular. But someone has to speak for the women and families who find themselves in the most heartbreaking situations. Someone has to remind everyone that while these bills speak in abstracts, the people affected have to live with the very real and very difficult ramifications. Our opinions are our own, but a person's philosophical beliefs cannot be inserted into the lives and decisions of other people. We cannot tell a person that they do not have the right to make a choice simply because there is a belief that they may regret it later or because someone's belief system is counter to their own.

As human beings, we are given two very distinct gifts: free will and intellect. I choose to respect them. I choose to err on the side of personal freedom because I know that my own beliefs are not the same as others. It is my hope that this committee will do the same. These decisions are moral ones,



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House Fed and State Committee

P.O. Box 8249 • Wichita, KS 67208 • 316-691-2002 • 316-691-8267 Fa February 20, 2008

Attachment

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religious ones and especially, these decisions are private ones. These decisions are not for activist groups or even well-intentioned members of government.

This is a room full of exceedingly lucky people. Most of us have never been faced with the painful and difficult decisions faced by uncounted of families every year. The anguish and the heartbreak we've heard about today has never visited my home. I sincerely hope the same is true for each of us. But for the families who *do* have to face these terribly difficult decisions, the right to make the choice that is best for their own situations must be preserved. These stories are about closure, about families saying goodbye on their own terms. I ask that you view this circumstance with an open mind and think of what you would do if you, your family, your wife, or your daughter were faced with a heartbreaking situation. I think you'll find that there are only difficult choices in these terrible circumstances, and the right choice is the choice that makes the situation slightly more bearable for each individual family.

I want to thank the committee again for being able to testify here today. As you watch the DVD of Miriam Kleiman and Jason Steinbaum, I hope you'll watch with an open mind and understand that each family simply wants to make the best decisions for them at that moment in time. Thank you again for this opportunity.

Respectfully,

Julie Burkhart



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Julie Burkhart
Chair

Lyndsay Stauble
Treasurer

OR
PRINT IN
PERMANENT
INK

Report of Induced Termination of Pregnancy

State File Number

INSTRUCTIONS SEE HANDBOOK

1. Provider Identification Number				State File Number			
2. Patient ID Number		3. Age on Last Birthday		4. Married <input type="checkbox"/> Yes <input type="checkbox"/> No		5. Date of Pregnancy Termination Month Day Year	
6a. Residence US State or Country		6b. County		6c. City or Town		6d. Inside City Limits <input type="checkbox"/> Yes <input type="checkbox"/> No	
7a. Hispanic Origin <i>(Check the box or boxes that best describes whether the individual is Spanish, Hispanic, or Latina, or not Spanish, Hispanic, or Latina)</i>		7b. Ancestry <i>(Enter the name of the country that best describes the heritage or origin of the individual)</i>		8. Race <i>(Check one or more races to indicate what the individual considers herself to be)</i>		9. Education <i>(specify only highest grade completed)</i>	
<input type="checkbox"/> Not Spanish, Hispanic, or Latina <input type="checkbox"/> Mexican, Mexican American, or Chicana <input type="checkbox"/> Puerto Rican <input type="checkbox"/> Cuban <input type="checkbox"/> Central American <input type="checkbox"/> South American <input type="checkbox"/> Other Spanish, Hispanic, or Latina (specify) _____ <input type="checkbox"/> Unknown				<input type="checkbox"/> White <input type="checkbox"/> Black or African American <input type="checkbox"/> American Indian or Alaska Native Principal Tribe(s) _____ <input type="checkbox"/> Asian Indian <input type="checkbox"/> Chinese <input type="checkbox"/> Filipino <input type="checkbox"/> Japanese <input type="checkbox"/> Korean <input type="checkbox"/> Vietnamese <input type="checkbox"/> Other Asian (specify) _____ <input type="checkbox"/> Native Hawaiian <input type="checkbox"/> Guamanian or Chamorro <input type="checkbox"/> Samoan <input type="checkbox"/> Other Pacific Islander (specify) _____ <input type="checkbox"/> Other (specify) _____ <input type="checkbox"/> Unknown		<input type="checkbox"/> 8th grade or less <input type="checkbox"/> 9th-12th grade no diploma <input type="checkbox"/> High school graduate/GED <input type="checkbox"/> Some College - no degree <input type="checkbox"/> Associate degree <input type="checkbox"/> Bachelor's degree <input type="checkbox"/> Master's degree <input type="checkbox"/> Doctorate <input type="checkbox"/> Unknown	
10. Date Last Normal Menses Began Month Day Year		11. Clinical Estimate of Gestation <i>(Weeks) (1)</i>		12. Previous Pregnancies <i>(Enter number or zero in every section)</i>			
				Live Births 12a. Now Living 12b. Now Dead		12c. Previous Induced Abortions 12d. Spontaneous Terminations (Miscarriages, Fetal Deaths)	
13 TERMINATION PROCEDURES							
13a Procedure that terminated pregnancy <i>(Check only one)</i>				13b Additional procedures used for this termination, if any <i>(Check all that apply)</i>			
<input type="checkbox"/> Suction Curettage <input type="checkbox"/> Sharp Curettage <input type="checkbox"/> Dilatation & Evacuation <input type="checkbox"/> Medical Procedure I (Mifepristone) <input type="checkbox"/> Medical Procedure II (Methotrexate) <input type="checkbox"/> Intra-Uterine Prostaglandin Instillation <input type="checkbox"/> Hysterotomy <input type="checkbox"/> Hysterectomy <input type="checkbox"/> Digoxin/Induction <input type="checkbox"/> Partial Birth (2) <input type="checkbox"/> Other (Specify) _____				<input type="checkbox"/> Suction Curettage <input type="checkbox"/> Sharp Curettage <input type="checkbox"/> Dilatation & Evacuation <input type="checkbox"/> Medical Procedure I (Mifepristone) <input type="checkbox"/> Medical Procedure II (Methotrexate) <input type="checkbox"/> Intra-Uterine Prostaglandin Instillation <input type="checkbox"/> Hysterotomy <input type="checkbox"/> Hysterectomy <input type="checkbox"/> Digoxin/Induction <input type="checkbox"/> Partial Birth (2) <input type="checkbox"/> Other (Specify) _____			

1 If clinical estimate of gestational age is 22 weeks or more, complete reverse side of form
2 If Partial Birth Procedure as defined by KSA 65-6721 is used, complete reverse side of form

Complete the following items only if the clinical estimate of gestational age is 22 weeks or more

14. Reasons for determining gestational age 22 weeks or more

15a Was fetus viable?

YES NO

15b Reasons for the determination

Complete 16a-c only if 15a is yes

16a Was this abortion necessary to
(Check all that apply)

- Prevent patient's death
- Prevent substantial and irreversible impairment of a major bodily function

16b Reasons for determination

16c Basis for determination

Complete the following items only if a partial birth procedure was performed

17a Was fetus viable?

YES NO

17b Reasons for determination

Complete 18a-b only if 17a is yes

18a Was this abortion necessary to
(Check all that apply)

- Prevent patient's death
- Prevent substantial and irreversible impairment of a major bodily function
 - If so, was the impairment
 - Physical
 - Mental

18b Reasons for determination

5-2



**Written Testimony of Holly Weatherford,
Kansas Public Affairs Manager of
Planned Parenthood of Kansas & Mid-Missouri,
in opposition to House Bill No. 2736
before the
House Federal and State Affairs Committee
of the Kansas Legislature
February 20, 2008**

House Fed and State Committee
Februruary 20, 2008

Attachment

6

Good afternoon. My name is Holly Weatherford and I am the Kansas Public Affairs Manager for Planned Parenthood of Kansas and Mid-Missouri. Thank you for this opportunity to submit written testimony about our opposition to House Bill No. 2736. Our not-for-profit organization offers sexuality education, advocacy opportunities, family planning services and a number of surgical services—including abortions—to Kansans in four locations. One of our most important goals is to help men and women make responsible choices that prevent unintended pregnancies. More than ninety percent of our patients come to our agency for family planning and other preventive health services.

Planned Parenthood is founded on the belief that every woman should be safe and healthy. Among other things, a woman's safety and health depends on her ability to determine for herself whether and when to be pregnant and to have a child. The ability to make decisions about childbearing without interference and regardless of geography, economic circumstance, or political considerations, is the most fundamental civil and human right, supported by more than 35 years of constitutional case law.

The constitutional right to privacy protects women's right to make personal decisions about their medical care without undue government influence. Under the right to privacy, state governments may restrict abortion only to further legitimate state interests in potential life or maternal health. While the opponents claim their efforts are related to maternal health, placing burdensome and unfair obligations on the provision of abortion services does not improve or protect the health of the woman. Planned Parenthood opposes this legislation in its entirety because we value the health and well-being of our patients, including minors and adults.

It is clear the intent of HB 2736 is to erode access to abortion services at the risk of women's health and lives. The proposed changes in HB 2736 may result in more delayed abortions, which thereby increase costs and risks. To argue differently stretches credibility. Women's health and lives will be endangered by illegal and unsafe procedures if bills such as this continue to reduce access to legal, safe abortions.

6-2

Although Planned Parenthood opposes this bill in its entirety, I will highlight two sections as examples of how these proposed changes erode access to abortion services. Section (3)(i)(1) to (i)(4) of HB 2736 creates a cause of action for injunctive relief that may be sought by an adult woman's spouse, sibling, parent or grandparent and more troubling any public official with jurisdiction to prosecute or enforce the laws of Kansas. It is understood that this is current injunctive relief language found in Kansas law, but when applied to the issue at hand, this section is clearly designed to create a substantial obstacle for women who seek abortion services. This section takes away an adult woman's decision making ability and places that choice in the hands of various family members and public officials. This cause of action will most definitely result in additional legal proceedings, forcing a woman to delay the abortion even later into her pregnancy or forces her to bear the child against her will. These delays are not in the best interest of women or the State and the State should not be dictating decisions so fundamental as whether or not to procreate that a woman is forced into bearing a child.

Another example is the changes in Section 4 of HB 2736. This section might be aimed at strengthening protections already in place for minors, but in practice will make it more difficult for minors to obtain abortion services. This section requires minors to produce photo identification, defined to include official school-issued picture identification, and verification of the minor's state of residence. Not all schools, in Kansas or other states, issue picture identification or identify in what state the school resides. What then is the recourse for a minor who has no school issued picture identification, driver's license or other government issued photo identification? In addition, how would this minor verify their state of residence? Is additional documentation required to verify state of residence? If so, what is acceptable? Again, this section creates another obstacle for young women who seek abortion services, resulting in burdensome and risky delays that are not in a minor's best interests.

Unfortunately, the proposed changes in HB 2736 appear to be in direct conflict with a desire to protect the health and well-being of women. We all know that eliminating access to safe abortions doesn't eliminate access to unsafe alternatives. Abortion has always been, and will always be, available through self inducement, back alleys or by

demonstrably safe medical procedures. Planned Parenthood urges this Committee and the Kansas Legislature to keep abortion safe and legal by opposing HB 2736.

I would like to devote the rest of this testimony to address the concern that women who seek abortions are not adequately informed when making their decision because they are not offered the opportunity to view the ultrasound image. In an effort to fully inform our clients, it has long been a standard practice at our affiliate to allow women seeking abortion services the option to view the ultrasound image at their request. Moreover, Planned Parenthood Federation of America recently revised their Medical Standards and Guidelines to make clear that any client who undergoes an ultrasound for any reason must be offered the opportunity to view the ultrasound image. This policy will go into effect June 2008. Standards which stipulate that a woman must be offered the opportunity to view her ultrasound image fall under the umbrella of patients' rights to their health care information and their medical record, is good customer service and reinforces the belief that clients are making decisions that are right for them. It is important for this Committee to recognize that the woman should not be forced to view the ultrasound image. The offer must be made in a compassionate, non-judgmental way—without raising an expectation that she must view the image—allowing each women to make her own personal choice in this situation.

Thank you.

6-4

February 20, 2008

HB 2736 with its many provisions, redundancy, flaws and unnecessary requirements, is an overly broad and unconstitutional piece of legislation. A political agenda is being pushed into the legal system, creating disruptive mechanisms that further restrict women's ability to access protected health care. Our legal system stands for the rule of law and freedom from those who would use it in order to grind a personal axe. But this bill would allow just that. For example, HB 2736 expands access to physician's names and facilities to any district or county attorney in the state, even if that government official does not have the authority or jurisdiction to prosecute the suspected violations. This has the potential to violate patient and physician informational privacy standards and to be unconstitutional.

This bill creates significant and unreasonable burdens on the legal access to abortion for women in Kansas, it does not provide any benefits for women; rather it creates additional unnecessary and unreasonable hurdles for women seeking safe and legal abortions. One can only conclude that the underlying premise of HB 2736 is to further burden and interfere with women obtaining legal abortions. The Kansas legislature must work to improve, not undermine, reproductive health care. Rather than interfering with physicians' ability to use their best judgment providing health care for their female patients the legislature should be more concerned with protecting the constitutionally guaranteed reproductive health care rights of women in Kansas. HB 2736 wrongfully interferes with a woman's right to choose matters regarding her health care with the advice of her physician and her family. For example, HB 2736 places obstacles

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in the way of the trusted adult who is accompanying a minor to obtain pregnancy information and counseling prior to an abortion, by requiring government issued identification from the adult and school-issued identification from the minor. This is an additional unnecessary burden on minors seeking abortions and caring family members at a time of significant medical needs. Additionally, some populations of adults may not have government issued identification. This requirement would have a disproportionate impact on those adults. This is just one example of the bills many overly broad requirements.

Existing Kansas abortion laws presently protect all parties and prevent abuse of the system. Doctors are already required reporters in cases of suspected abuse or statutory rape. Thorough reporting is already mandatory to KDHE and those statistics are published. Medical procedures can not be preformed without informed consent. Most, if not all reproductive health care providers use ultrasound technology. Late term terminations are well regulated, taking into account a woman's right to her own health care. The language in HB 2736 ignores all existing regulations. HB 2736 is unnecessary legislation.

It is my assertion that even if the private, confidential medical records of women who have sought reproductive health care services could be plastered on bill boards along the Turnpike that that would still not be enough to mollify those who support these kinds of bills. The simple truth is that there are some who will stop at nothing to see abortion banned altogether, while they have a right to those opinions, those opinions must not be permitted to deny a woman's right to a legal and safe abortion. Bills like HB 2736 are intended to chip away at a constitutionally protected right and continue down a slippery

slope to back alley abortions. If abortion is to remain safe, it must first be legal. We must not allow back alley abortions to return. The health and safety of American women seeking abortion mandates that abortion be kept legal so that they may be regulated and safe.

Viability, physical health, and mental health are issues to be determined by doctors, not lawmakers. It is the responsibility of elected officials to protect and respect the rights, privacy and lives of the people, including women. This bill adversely infringes on all aspects of women's right to reproductive health care. Because every case is different, every case unique every woman must be able to make choices about her own life and health with the assistance of a competent doctor and the support of those she chooses to engage. Believe me when I tell you, unless invited, you, the Kansas Legislature, does not belong in those private discussions.

I thank you for your time.

Sincerely,

Pedro Luis Irigonegaray
Attorney at Law
Topeka, KS