

Testimony by Alexandra Fraser, PhD to Kansas State Senate on Senate Bill 509,
“Women’s Health and Embryo Monitoring Program Act”

I would like to express my thanks to the Senators of my home state of Kansas for accepting my testimony on Senate Bill 509. I have a PhD in Biology from the University of Kansas. While I was pursuing this degree I decided to sell my eggs to help fund my graduate studies. The results were disastrous for my short-term and long-term health. Although I am a scientist, the purpose of my testimony is to tell my personal story of selling my eggs in the state of Kansas with the goal that in the future young women in Kansas will be spared significant dangers to their health. I believe that my story illustrates the need for a registry of egg donors, long-term studies to track the health of egg donors, and a decoupling of egg donation from monetary compensation.

The decision to sell my eggs: In 2002 I was 29 and all-but-dissertation for a PhD in biology at the University of Kansas. I had a job at the university making about \$800 per month, which barely covered my living expenses. This research position kept me quite busy and I could not find time to write my dissertation and complete my degree. At this point I had been in graduate school for eight years, and I felt discouraged by the poverty and criticism that accompanies graduate study. I was in love with a young man who was waiting for me to join him another city, and I was desperate to complete my education and move on with my life. I calculated that three months of income would allow me to complete my degree. I looked into student loans, bank loans, and borrowing money from family but none of these options were feasible for me. I started looking for other ways to obtain \$2400.

For years I had seen ads in the *Pitch Weekly*, a Kansas City area entertainment paper, advertising for egg donors. I figured, “Why not try to earn money from something I wasn’t using?” I visited the university library and searched the medical journals for literature about the risks of egg donation and found nothing, thereby assuming it was not dangerous. After doing some online research I learned that I could work with either a local fertility clinic, or a broker who would arrange for me to sell my eggs to a couple in another city. I liked the idea of being seen and tracked by a local doctor. After finding the website for a reputable fertility clinic in the greater Kansas City area, I applied to sell my eggs. Money was my primary reason for selling my eggs, but my online research left me with a positive impression of the process: that I would be helping others, that the process involved a relatively low time commitment (that is, compared to working for \$10 per hour), and that it was safe.

Screening and Informed consent: Through the fertility clinic, I went through a multi-stage screening process that included applications, review of information sheets, one meeting with the doctor who would perform the procedure, and multiple meetings with a nurse practitioner. The screening process focused on my genetic fitness, that is, my family history of disease, my sports and academic background, and photos of me as a child. The psychologist for the clinic also screened me for mental health issues.

I was selected to be the donor for two recipient couples who would share my eggs. I agreed that the process would be anonymous. I would not know the couples, nor would I know whether or not a child was conceived with my eggs. It was flattering to be selected, and I found the medical technology behind the process to be fascinating and exciting. I signed a contract to sell my eggs. The total compensation – which was described as a stipend for my time rather than payment for my eggs – would be \$2750.

At the time I signed my contract, the nurse practitioner described the possible side effects. I was told that hyperstimulation could occur, and that infertility was possible but highly unlikely. I do not remember now whether or not she mentioned cancer as a possible risk. The list of risks was lengthy but they were presented as though they were remote. I found them to be similar to many of the potential side effects for birth control pills. I was told that the most dangerous thing about selling my eggs would be the frequent drive down K-10.

The donation and retrieval process: Over the next several weeks I took a series of drugs to match my reproductive cycles to the recipient mothers, drugs to stimulate my ovaries, and drugs to ripen my eggs. Each evening for a couple of weeks I would inject myself in the thigh with a syringe, and each time I would pray for the health of the recipient mothers and that my body would make healthy eggs for them. I did know that I should have been praying for my own health.

In the week prior to the retrieval, my abdomen began to swell. I was gaining fluid and my ovaries were enlarged. I was told that my ovaries were mildly hyperstimulated, but that it was safe to move forward with the retrieval. On September 12, 2002 I underwent anesthesia, and the doctor removed 28 eggs from my right ovary using a trans-vaginal, ultrasound-guided needle. I went to a friend's house to rest and recover. Over the next several days the swelling went down. A few days after the retrieval, I was feeling pretty good. I visited the clinic again, was told I was doing fine, and we discussed the possibility of beginning another donor cycle the following month. At this point, my experience with selling my eggs was very positive.

Ovarian hyperstimulation and torsioned ovary: A little more than a week after the retrieval, on September 21, 2002, I awoke with a searing pain in my abdomen. When I tried to walk into the bathroom I lost consciousness from the pain. It felt as though my insides were being tied tightly with a string. A friend drove me to the clinic. It was a Saturday so I saw the on-call doctor. She performed an ultrasound and said it was nothing more than my follicles shedding and that the pain would go away in a few days. She said, "If anything serious were wrong, you would know. You wouldn't have been able to walk into the clinic." Over the next three days my abdomen swelled, I was delirious with pain and fever, moving in and out of consciousness, and I couldn't move my bowels. Another friend drove me back to the clinic, where the nurse told me I needed an enema and to eat something and I would be fine. However, whenever I ate I would vomit. On the fifth day I couldn't stop vomiting. I spent an entire night vomiting stool.

The clinic agreed to see me again, yet another friend drove me to the clinic and I finally saw the doctor who had performed the retrieval. He went white when he saw my distended abdomen, and he had me on the operating table in thirty minutes. He removed my right ovary, which had swollen to the size of a grapefruit and become torsioned in my fallopian tube. I had an infection and was on the verge of peritonitis, and I had lost a lot of blood. I was admitted to the hospital — ostensibly for a day or two — but stayed two weeks because my bowels were still obstructed. For a week I had a nasogastric tube to apply suction to decompress my intestines. I had a port installed in my chest to receive liquid nutrition. Overall, I was confined to bed for almost four weeks. I lost more than twenty five pounds on my 135 pound frame, and I looked like a skeleton at the end of my hospital stay.

From the point at which I was diagnosed with the torsioned ovary, the clinic spared no expense. They got the best gastroenterologist to see me daily. The clinic put my mother up in a nice hotel near the hospital. The fertility doctor saw me daily. When I was discharged, they kept my mother and me at the hotel for another week so that they could check on me. I did not have health insurance but I never saw a bill from my surgery or my hospitalization.

I do feel that the clinic should have diagnosed my torsioned ovary earlier. Once they recognized the severity of my situation, I feel they did make a sincere effort to do the right thing. I am glad that I was working with local doctors who knew me and not an egg broker or a fertility doctor across the country that only saw me for the retrieval. Nonetheless, the donation made me very sick and I can never get my ovary back.

Since that time, I regained my strength, moved away, married the young man who was waiting for me, and got a great job. It seems ridiculous now that I was so desperate for \$2400. I certainly regret selling my eggs, but I thought it was behind me.

Cancer: Almost five years to the day after my egg donation, I was diagnosed with stage II B breast cancer. I was only 34 years old and was otherwise vigorously healthy. I didn't have just a little bit of cancer: I had a three centimeter tumor tucked into seven centimeters of pre-cancerous cells. The disease was on (but not in) my chest wall. I also had pre-cancer throughout my other breast. I underwent a mastectomy, four months of chemo, followed by three more surgeries and twenty eight days of daily radiation treatments. A few months after finishing radiation I had another mastectomy. I feel very fortunate that I now show no signs of cancer. However, I am only 36 but I have lost both breasts and I have only a 65% chance of making it to age 45 free of cancer. Even if I survive, my doctors have informed me that the chemotherapy has fried my remaining ovary and I am not able to have children.

I believe that selling my eggs contributed to my breast cancer. Although I cannot prove this relationship, the following reasons suggest a link:

- My health has always been excellent with no major risk factors for breast cancer. I had no significant family history of breast cancer and do not carry either of the known breast cancer genes (BRCA1 or BRCA2).
- Complications of selling my eggs are the only irregular conditions in my health history.
- Most breast cancers, including my tumor, are stimulated by hormones. Thus the mechanism exists by which ovarian stimulation could trigger tumor growth.
- The fertility drugs I took were originally developed to stimulate infertile women. Their effect on healthy, young, fertile women is likely to be different.
- Some studies indicate that the hormonal effects of pregnancy offset the risk of taking fertility drugs. Because egg donors do not become pregnant, they do not experience these benefits.
- Two doctors in the oncology field have told me that anecdotally, they see more breast cancer in women who have undergone IVF or egg donation.
- My support group for young women with breast cancer includes other women who were egg donors or experienced unsuccessful IVF cycles.

Conclusion: As a result of selling my eggs, I survived a torsioned ovary, intestinal failure, and a body cavity infection. I have also survived breast cancer, including having both of my breasts cut off, and eighteen months of harrowing chemotherapy and radiation treatments. I am grateful to be alive, but I believe that all of this could have been avoided if I had not sold my eggs – a procedure that I thought was safe. We native Kansans live proudly by our state motto, *Ad astra per aspera*. Although I survived, I believe that I suffered this adversity needlessly, and I hope that other women will not suffer as I did.

A registry of donors, including frequency of complications, would have led me to make a more informed choice. I fear that right now a young student at KU or Kansas State or another of our fine Universities is considering selling her eggs. She will not be provided with any real numbers about the risks she faces. Only long-term tracking and studies can adequately address cancer risk from egg donation. Most women who get cancer after selling their eggs will not be diagnosed for several or many years later – longer than the three to five years of data in most research studies. For example, my cancer diagnosis and my history as an egg donor do not appear in any medical literature or statistics about egg donor outcomes.

My mother, who rushed to my side when I was sick, sometimes cries that I sold her grandchildren away. She bemoans that I almost lost my life not once, but twice – all for only \$2750 dollars. I think about how eager I was to move close to my boyfriend-turned-husband, and how selling my eggs has jeopardized our future together, and the possibility of having our own children. It caused me to have both of my breasts cut off, which affects my young marriage and my sense of femininity. I realize now how vulnerable I was when I was poor, frustrated, lonely and trying to finish my education. Everyday I have to live with the consequences of this stupid, ill-informed decision I made when I was 29. Eliminating the financial compensation for human eggs will spare other women from my fate.