

It's Time for an Egg Donor Registry and Long-term Follow-up

Testimony at Congressional briefing
by Jennifer Schneider, M.D.
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Although not a transcript, this is an accurate record of what I said on November 14, 2007 at a Congressional briefing on human egg trafficking co-sponsored by Marcy Kaptur (D-OH) and Joseph R. Pitts (R-PA).

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1. Summary:

I'm a physician. I'm also the mother of a young woman who, like thousands of other college students at elite universities, decided to supplement her income by donating her eggs for money. And like all other egg donors, she did it without understanding that the long-term risks of this procedure are unknown. She underwent the procedure 3 times, and then went on with her life. Six years later she was dead of a disease that usually affects people my age, not hers – colon cancer. She had no family history of this disease, and genetic studies of her tissue subsequently showed that she was not at genetic risk of colon cancer.



Since her death I've researched what is known about the long-term risks of colon cancer in egg donors, and I'm here to tell you that hardly anything is known, because once a young woman walks out of an IVF clinic, she is of no interest to anyone. No one keeps track of her health. In fact, the people who benefit from egg donations – IVF clinics and researchers, have every reason to avoid follow-up of egg donors and studies of their possible long-term risks. (After Jessica's death I learned the name of her egg broker and phoned her. I told her Jessica had died of a potentially genetic disease and the broker needed to tell the recipients of Jessica's eggs about this, because their child/children will need to be tested. The broker told me that she only keeps records for a few years, and had already destroyed all records pertaining to Jessica, so that the broker no longer had information about who were the recipients. Very convenient!)

The IVF clinics make enormous sums of money from egg donation, and the researchers want to maximize the number of eggs they have. That's why, as in Great Britain, we need government intervention. I'm here to tell you why I think it is very important for Congress to mandate egg donor registries, and keeping track of egg donors.

2. Jessica

Jessica (See attached photo) fits the classic description of an idea egg donor: beautiful (she modeled in her teens), bright (Stanford graduate), tall (6 feet tall), athletic, talented, artistic. A short film she made at college won the first prize for best short film that year at the San Francisco Film Festival. She composed songs, played piano and guitar, and was lead singer in a rock band at college. Later she composed more classical musical.

When Jessica phoned me to tell me she was considering being an egg donor, I said, "My main concern is your safety. Is this safe?" She said, "They told me there are some risks associated with the procedure, such as bleeding or infection, and that's about it." She said, "I'm having this done at a very respected IVF clinic. I'm sure they'll take good care of me." Even though I'm a highly trained medical professional, I assumed that what she was telling me was the facts. The first time she donated her eggs, a pregnancy resulted. This made her a "proven donor," an even more desirable category. A couple of months later, the egg broker phoned her to say another couple wanted to use her, and was willing to pay twice as much. She did 3 egg cycles in all.

Jessica then entered a graduate school program in film making, and was finishing up her master's degree when she developed abdominal pain. A work up showed advanced colon cancer, very unusual in a 29-year old. I knew that average survival with the best treatments available was 18 months. Jessica had to drop out of school. She underwent chemotherapy, massive surgery, and radiation when she developed metastases in her bones and then her brain. She then developed metastases in her lungs and gradually lost her ability to breathe. She died at age 31.

During her almost 2 years of fighting her cancer, she composed a musical based on the story of "Hansel and Gretel." Her theater company planned to mount a production of this musical, and Jessica's greatest wish was to see it performed. She brought her computer with her to chemotherapy sessions and hospitalizations, and continued composing while lying in bed.. But she died 3 weeks before her musical premiered at the New York International Fringe Festival, where it won

a prize for Best Music for that year, 2003. The New York Times Arts section had a lead article about Jessica and her musical. It was titled, "Premiere Draws Crowds and Tears for Absent Composer." (See attached document). The NBC Today show ran a piece about Jessica.

Her death was unexplained. When she was first diagnosed, the first thing she – and I – thought of was could it have been the large doses of hormones she received for the egg retrieval. Jessica asked her oncologist, who told her that there was no evidence supporting a role of ovarian hyperstimulation in causing colon cancer.

But last year I ran across an article by Dr. Kamal Ahuja, a specialist in in vitro fertilization (IVF), that described a young woman who donated eggs for her infertile sister, and a few years later was diagnosed with advanced colon cancer and died. This got me thinking seriously about the possible role of ovarian stimulation in causing her colon cancer. I began doing a lot of reading, and communicating with specialists in the field. What I learned was very disturbing. Here is what I learned:

- Egg donors are commodities.
- Long-term risks of egg donation are unknown.
- IVF clinics and researchers have a serious conflict of interest.
- The government needs to intervene.

3. Egg donors are commodities

- The first baby born by in vitro fertilization (IVF) was born in 1978.
- The first IVF baby using a donated egg was born in 1984
- In 1992 there were about 1800 egg donor cycles.
- In 2004 there were 15,175 egg donor cycles.
- This exponential increase is escalating further now because of the new huge demand for eggs for stem cell research.

A front-page article in the *Arizona Daily News* on Nov 4, 2007 (originally published in the *Minneapolis Star Tribune*) was titled "New life for sale: Human eggs focus of booming, \$3B industry." Some quotes:

Caitlin K. sees it as a classic case of supply and demand. After all, one of her eggs goes to waste every month, so she might as well share it with a woman who can use it. She thinks the \$8,000 she can get is a reasonable price for helping someone create a life...Caitlin K, 24, is a bit player in a \$3 billion business that is thriving on the Internet...But as it flourished, some are warning that the freewheeling marketplace is turning the creation of human life into a commercial enterprise that cries out for consumer protection. Nowhere is this more evident than in the exploding market for human eggs, where there are few laws protecting the rights and health of donors and parents.

More from the article:

Donors are becoming more savvy....Girls are doing it because it helps with their finances...Would-be parents pay the fee to the egg donor themselves, in addition to the \$15,000 or more that goes to the agency for insurance, and the donor's medical and legal costs.

The egg broker also profits with a hefty fee. And the medical insurance purchased for the egg donor undoubtedly does not cover late medical costs, such as was the case with Jessica's illness.

- Egg donors are not followed up.
 - They don't have their own doctors.
 - The known short-term risks (ovarian hyperstimulation syndrome) are underplayed (no one told Jessica anything about this, yet young women have died).
 - Long-term risks are not known.
 - Egg donors sign consent forms without knowing the risks, because the risks are not known.
 - Once they leave the IVF clinic they are of no interest to anyone.
- Role of the Internet.

The above article mentions a web site called Egg Donation Inc, so I visited it. Its motto is "Where Dreams Come True. It claims to be the oldest and largest donor website in the world, with a stable of over 1,000 available egg donors. This detailed website discusses medical, legal, and psychological issues. Its emphasis is on altruism, although the reality is that the main motivator for egg donors is money. It provides testimonials from 2 egg donors. One says, in part, "Even since my teens I've wanted to do something that will make a difference in someone else's life." The other says, in part, "The opportunity to help someone else without wanting something back really only comes around a few times in life." The web site says nothing about risks, other than in the legal section it states "medical professionals will discuss risks."

Yesterday I googled "egg donation" and got 487,000 hits. Many offer payment for egg donors. Some list extremely specific characteristics they seek – particular ethnic types, religion, eye color, type of education and interests, etc. – and

offer sums as high as \$100,000 for the right donor.

Young women are lured by these offers. The risks are minimized. Additionally, the young women are unlikely to understand the huge difference between the statements "There are no known long-term risks," and "There are no long-term risks." Moreover, the quick money overwhelms any real attention to potential risks. Potential egg donors need their own doctor, they need an impartial person who can counsel them and who is not a part of the egg donor industry. Instead they are perceived as commodities rather than as individual human beings of value. Instead, they are counseled by employees of the egg broker and the IVF clinic, who naturally want as many women as possible to sell their eggs.

4. What is known about the risks?

There have been no long term studies of egg donors. There is a real need for such studies. But they will not happen until there is a mandatory egg donor registry, so that there is contact information for egg donors and they can be followed up for years.

Here's what we know so far about the relationship between hormonal stimulation and cancer:

1. Studies of infertile women who have had ovarian stimulation in order to harvest their own eggs. (They are not comparable to young egg donors – older; infertility itself is associated with increased risk of some cancers; if they get pregnant subsequently, the hormonal milieu of pregnancy may mitigate some of the effects of ovarian stimulation.) A study of over 12,000 such infertile women was published in 2005 (Altuis et al). It found a 1.8 fold increase in the risk of uterine cancer following ovarian stimulation. The study didn't follow enough women for a long enough time, but it did find that the longer the greater the number of years since donation, the greater the risk of breast cancer.

2. Studies of effects of female hormones in general: It is known that treatment with estrogen causes an increase in the risk of estrogen-related cancers such as breast and ovarian cancer. In the past few years, now that fewer women take hormones after menopause, there has been a decline in breast cancer. Women who have a uterus and take estrogen are at increased risk of uterine cancer, which is why they are also advised to take a progesterone, which counteracts the increased risk.

3. Private agencies, researchers, and even professional organizations have conflicts of interest. Why are private agencies not interested in the well-being of egg donors? Because they have a lot to gain from encouraging egg donors – money from desperate infertile couples, and eggs for research. IVF clinics are highly lucrative. They are the "cash cows" of university Ob-gyn departments. Researchers want as many eggs as possible.

There is now research taking place on "natural" IVF. Women don't need to be given high doses of hormones in order to produce a single egg – they do it once a month on their own. It's possible for IVF clinics to obtain a single egg from an egg donor without stimulating her ovaries, and it's clearly safer. But it's also a lot less efficient – several months of ultrasounds and egg retrieval may be necessary for a pregnancy, and certainly researchers will get fewer eggs for research. So IVF clinics and researchers are interested in getting as many eggs as possible, which involves high doses of hormones.

In 2006 the American Society of Reproductive Medicine's Ethics Committee published guidelines on payments to egg donors. They suggested a "reasonable" fee of \$5,000, and a maximum of \$10,000. But they did not put in place any way of enforcing these guideline, which are widely ignored. The members of ASRM are primarily physicians working in IVF clinics, the same clinics who want to attract as many donors as possible, by offering them increasingly large fees.

4. The government needs to intervene.

Private agencies and researchers can't be expected to police themselves. This reality has been recognized in other countries. Great Britain, Canada, and Israel all have outlawed the sale of eggs. Eggs are similar to other organs, and the sale of organs is outlawed in the U.S. The sale of organs is outlawed because otherwise the financial incentives may outweigh consideration of the donor's best interest. The US, on the other hand, seems to consider egg donation in the same category as sperm donation rather than subject to existing laws regarding organ donation. Clearly, sperm donation does not involve risks, unlike egg donation.

There is urgent need for proper oversight and medical care of egg donors. There are two patients - the infertile woman and the egg donor, It's time that the egg donor cease to be the forgotten member of the team. This country needs a comprehensive egg donor registry, which will enable research on the long-term effects of egg donation.