

Fertility Unregulated

SULEMAN'S OCTUPLETS BEG THE QUESTION: IS IT TIME FOR THE BABYMAKING BUSINESS TO BE REGULATED?

BY CINDY MORGAN

It's official: the newest celebrity mom is one of us. Nadya Suleman, a.k.a. Octomom is now an Orange County mom. No matter what you think about the choices Suleman made in becoming a mom 14 times over, her story illustrates how fertility medicine has given women power over how and when they have children—and how many. Approximately 15% of the population is infertile—add to that the large number of women who delayed starting a family and you have thousands of people each year turning to fertility specialists for assistance in conceiving. Up to this point, fertility medicine has been largely self-regulated, but Suleman's and several other high-publicity fertility scandals have many people asking if it is time to impose greater regulations on the baby-making industry.

IVF Explained

Like thousands of other people struggling with fertility problems, Nadya Suleman used IVF (in Vitro Fertilization) to conceive her 14

children. IVF is the most involved and expensive fertility treatment with costs that can easily exceed \$15,000 per cycle for those whose insurance doesn't cover treatment. The procedure involves fertilizing eggs outside the uterus and implanting one or more embryos after several days. Patients and their doctors decide how many embryos to implant based on the mother's age, the quality of the embryos, the woman's fertility history, and the published guidelines of the American Society for Reproductive Medicine (ASRM). For women under the age of 35 with no history of IVF and good embryo quality, the recommended number is 1-2 embryos. For women 35-37 it is two, and for women 38 to 40 it is three embryos. A woman over 40 may have up to five embryos implanted. The goal in all fertility treatments, including IVF, is a single pregnancy.

"We want to make fertility treatments succeed but we don't want to see higher order multiples," says Dr. Mark Kan of the Newport Fertility Center.

"Currently our clinic's rate of triplet births is low—around 1%."

In fact the number of multiple births generated by fertility specialists is dropping as doctors have improved their practices, including implanting fewer embryos per IVF cycle.

“Because of dramatic improvements in the laboratory we are implanting fewer embryos of better quality than we were five years ago.” Said Dr. Lawrence Werlin of Coastal Fertility in Irvine.

“The 2007 data of the Society of Assisted Reproductive Technology (SART) show that pregnancy rates are improving while the number of multiple births is declining.”

The ASRM data that Dr. Werlin cited show a triplet rate of around 2%. This is definitely an improvement, though the rate of naturally occurring triplets is approximately .01%.

Reputable fertility doctors follow the ASRM guidelines and only step out of them when they believe a case requires it. Doctors like Michael Kamrava (Suleman’s fertility doctor), are clearly flying in the face of accepted fertility practices and their actions have prompted many to question whether there should be stricter guidelines and perhaps oversight by an outside agency. Drs. Kan and Werlin agree that an outside agency would have a difficult time establishing and enforcing strict guidelines on how many embryos could be implanted per cycle because each patient’s case is different and needs to be treated individually.

“Limiting IVF to one or two embryos per cycle would be challenging,” according to Dr. Kan.

“I have several women who are pregnant with one fetus who never would have been able to conceive if we could only implant two embryos every time.”

Steven and Melissa James of San Clemente are a couple who had to make a tough decision about how many embryos to transfer when they were trying to conceive their second child last year. While it only took one IVF cycle to conceive the first child five years ago, they underwent four more cycles before they conceived again. Each cycle they implanted the recommended two embryos, but on their last cycle they decided to put in three.

“My doctor [Dr. Jane Frederick of Huntington Reproductive Center in Laguna Hills] is very strict about how many embryos to implant,” said James. “I had to persuade her to implant the third.”

For the James’ it was a good decision: Melissa delivered a healthy baby in March.

In fertility medicine today, the patient has the final say, though a responsible doctor will discuss the real and serious health risks to mother and infants in a multiple pregnancy and work to achieve the goal of a single pregnancy.

GAMETE DONATION

Nadya Suleman and other single mothers by choice, lesbian couples and heterosexual couples with male-factor infertility have turned to sperm banks to start families in recent years. With the sharp increase in

children conceived with donor sperm and eggs, many issues are surfacing that have clients wondering whether the industry needs closer, and perhaps, outside oversight. Of particular concern are issues related to medical reporting between donors, banks and offspring, and the number of offspring per donor.

The FDA regulates sperm banks for their quality and safety standards. Sperm is screened rigorously for genetic diseases and disorders. Donors are also required to submit detailed medical histories of themselves and their families. Sperm is as safe as the banks can make it, but many families have questioned whether that is enough. What if your child has a genetic disorder that the bank does not screen for that is traceable to the donor? What if the donor has health issues that develop years after he donated (most donors are college-age at the time of dona-

tion) that could affect his biological offspring? Should banks be required to report additional medical information to the parents and offspring?

Today, sperm banks are not required to follow up with donors or families and have resisted reporting issues to families even when there is significant medical evidence that a donor was responsible for passing on a genetic disorder to a group of offspring.

“It is like driving through Taco Bell and picking up your food,” said Beth Fogel a Fullerton single mother by choice who used an anonymous sperm donor to conceive her son 10 years ago.

“You just drive away and that is the end of it.”

For many families who decided to use donor sperm or eggs, the internet has changed the face of gamete donation and made it more difficult for sperm banks to ignore client concerns. The Donor Sibling Registry (www.donorsiblingregistry.com), a website begun in 2000 by Colorado resident Wendy Kramer and her son Ryan as a place for Ryan and other children conceived through anonymous gamete donation, has become a site with over 20,000 registrants and is a forum to discuss medical and ethical issues surrounding donation. Some of the posters are donors, most are parents who have posted the donor’s information of their young children, and others are grown children and adults searching for their biological fathers, mothers, or half-siblings.

Beth Fogel and Joan, another single mother by choice living in Orange County have both found half siblings of their offspring through the site. Like many members of the DSR community, they feel that sperm banks should have to maintain tighter records on births per donor and relevant medical information.

“Reporting live births to the bank should be required,” said Joan. “[Sperm banks] should give the numbers of live births to people.”

Currently, banks ask clients to report their live births. But even if they do, other clients interested in sperm from the same donor are not told how many live births have been attributed to a donor. Many clients select a proven donor (i.e. one who has live births that have been reported) hoping to get pregnant more quickly, not knowing if that donor has

“Nadya Suleman’s fourteen kids seem like a lot—but not compared to one group of over a hundred kids who share the same donor.”

FERTILITY RESOURCES

American Society for Reproductive Medicine (ASRM) is a non-profit organization devoted to advancing knowledge and expertise in reproductive medicine, including infertility and contraception. The website offers fertility information, fact sheets and links to find ASRM doctors in your area. www.asrm.org

Donor Sibling Registry (DSR) is a comprehensive, secure, and positive environment of information, studies, support, and resources for parents and their children. The site includes a blog and Yahoo Group. www.donorsiblingregistry.com

International Council on Infertility Information and Dissemination (INCIID) is a nonprofit organization that helps individuals and couples explore their family-building options. The website offers a wealth of information including studies, forums and chatrooms. www.inciid.org

Penny Joss Fletcher, MA, MFT Local therapist who offers counseling for couples or individuals experiencing infertility. She also counsels couples or individuals who are choosing to adopt. 714-730-7996. www.infertility2adoption.com

one offspring or one hundred.

Searching the DSR by clinic reveals one of the troubling aspects of sperm donation: there are many large groups of children who share the same donor. One of the largest banks in the nation, Fairfax Cryobank in Virginia, has groups of 24, 25, 28 and even 42 families who have the same donor. There are probably more who don't know about the site or have chosen not to post. Nadya Suleman's fourteen kids seem like a lot—but not compared to one group of over a hundred kids who share the same donor.

Some banks have adopted policies that limit the number of families who share a donor, likely in response to pressure from people like Kramer who have worked hard to publicize the problems stemming from a lack of oversight or regulation.

"This [educating the public]," believes Kramer, "is the only way to move the industry in the direction of more openness, and better education and counseling for recipients and donors at the front door—before they donate and decide to create their families via donor conception."

Because fertility medicine is a private industry in the United States, providers and consumers have been given the task of policing it. One problem with this model is that the consumers are involved at an emotional level not present when they are looking to buy a car or a flatscreen TV. They are trying to have children and many are willing to go to great lengths, financial and otherwise to make that a reality. The more times a person or couple fails to conceive, the more likely they are to become more aggressive in their treatments—pushing for more embryos to be implanted per cycle or choosing a sperm donor with a high number of reported pregnancies. These people are not necessarily looking for regulation and oversight. They are looking to conceive a child.

Dr. Kan of Newport Fertility Center points out that "No one in this country wants to be told how many kids they can have." He believes his patients would not favor outside regulation because it might interfere with their own ability to conceive.

Suleman's octuplet pregnancy reveals another flaw with self-regulation: some doctors do not abide by the best industry practices, and at this point there is no established system of punishment for abusers. Similarly, surrogacy clinics and sperm banks have been allowed to operate in the manner they see fit with little or no oversight. There are several recent court cases against surrogacy clinics in California that are accused of taking money from clients and not providing services.

Greater oversight and regulation may be on the horizon for the fertility industry, though it is unclear at this point what shape that might take. State senator Jesse Reynold (D-Chino) has recently sponsored a bill that would define fertility clinics and egg extraction sites as outpatient settings. If this happened, these sites would fall under the jurisdiction of the Medical Board of California and would then have accreditation standards and guidelines. But until regulation happens consumers need to be more cautious and better educated—a challenge when you enter the emotionally charged world of fertility medicine. Wendy Kramer's DSR project is first and foremost a way to refocus the fertility industry and its consumers on the children they are trying to create.

"For decades...no decisions were made, no policies set, based on considering what might be best for the children we were bringing into the world."

The choices we make in order to conceive our children will inevitably effect our children (consider how Octomom's choices are effecting her children), and Kramer suggests people think more about these repercussions before they conceive. That may mean choosing a non-anonymous or identity-release donor so children can know more about their biological roots. It may mean not sinking into debt in order to have biological children. It may mean considering all of the ethical repercussions of IVF (destroying remaining embryos, selectively reducing fetuses) before choosing that as an option. Because we live in a society that does not want someone else making important life choices for us, it is important that we do the best job we can of making these choices that have such a deep impact on the children we bring into the world.

MARKETPLACE NEWS

SPECIAL ADVERTISING SECTION

An Educated Case for Banking Cord Blood

Banking your baby's cord blood is a good thing to do. Why? Well, first and foremost, the stem cells found in your baby's umbilical cord may otherwise be disposed as medical waste. These precious stem cells found in your baby's umbilical cord would otherwise have the potential to treat your baby, a member of your family or a stranger in need of a transplant for a variety of diseases. Today, there are over 70 diseases that can be treated using stem cells found in cord blood. However, the most promising side of banking your baby's cord blood is future applications. According to researchers, the possibility of curing Type 1 diabetes, spinal cord injuries, corneal repair, Parkinson's, Alzheimer's, cancer, defective heart valves, and scores of other life threatening conditions is right around the corner. The potential for stem cells is unlimited.

While the important thing is that you bank your baby's cord blood—choosing a private family cord blood bank has some distinct advantages. In the event your child, you or potentially a member of your immediate family needs a transplant, the key is finding a human leukocyte antigen (HLA) match. What does this mean? In order for your body to accept a transplant of stem cells to treat a particular disease or disorder, your body must be able to recognize these stem cells as familiar, not foreign. If your body sees the transplant as foreign, it will reject the stem cells and the transplant will have little chance for success. If you have a high HLA match, the chances of your body seeing the stem

cells as familiar are greater, and thus the potential for a successful transplant is higher.

When you store your baby's cord blood with a family cord blood bank, the cord blood belongs to you. When you bank your cord blood with a public cord blood bank, you are donating your cord blood to the bank, and in the event your baby/child needs a transplant, you will not



have access to their cord blood and will need to find a suitable match. While seeking an HLA match among donors is certainly possible—30%-70% of people who need bone marrow transplants cannot find a match. Finding a proper match is especially problematic for African-Americans, Hispanics, Native Americans, and people of mixed ethnicity. Why? Primarily because these ethnicities do not have a high number of donated cord blood units to public cord blood banks.

When you use your own cord blood for a transplant, the HLA match is exact since the cord blood stem cells came from your own body. If you use your baby's cord blood stem cells for a member of your immediate family—the chance of an HLA match is greater than if you were to seek a stem cell match from a donor.

In closing, choosing to store your baby's cord blood either publically or privately is a good decision. The value of cord blood stem cells is far too important to let them be disposed as medical waste. Have more questions? Email Nurse Wendy at: AskNurseWendy@PacifiCord.com.

—Wendy Spry, LVN, CPSS and Healthcare Educator at PacifiCord