

## Conceivable Truths

Consumers are calling on sperm banks to facilitate information sharing between donors and their offspring.

By Kerri Penno

*Blond hair, blue eyes, 5'11", 175 pounds, olive toned, Armenian descent, works in international relations.*

No, this isn't a personal ad, this is actually a fairly typical description of a sperm donor printed in a donor catalogue distributed at fertility clinics. Donor descriptions can contain everything from a donor's education, to his baby photos, personal essay, celebrity look alike, shoe size and his amount of chest hair.

Surface health information includes blood type and cytomegalovirus IgG and IgM status. Delve deeper, and you'll find information on any allergies or conditions the donor has suffered, and any corrective procedures or actions he has experienced (e.g., braces, glasses, surgeries). Fertility clinics generally require detailed applications (20 pages or more), outlining medical history (theirs and their family members'), and tout their selectivity (only about 1 percent of applicants are accepted as donors).

Nevertheless, that's not enough, according to Wendy Kramer, executive director and founder of The Donor Sibling Registry (DSR). "That is just a snapshot of 1 day in the life of that donor," Kramer told *ADVANCE*. "That report doesn't tell you if the donor was later diagnosed with cancer, or if his father died of a heart attack the next day, or if half the children conceived with the donor's sperm went on to develop autism."

Yet donor-conceived children (DCs) face many roadblocks if they choose to try to locate their biological fathers for more information.

## The DSR

Historically, sperm banks have prioritized donor privacy, noting their donor supply would diminish greatly if privacy could not be guaranteed. That's why Kramer started the DSR. Her son, Ryan, is a DC, curious about his genetic roots from a young age. When he was 9, the Kramers ran into these privacy policies while trying to find any half-siblings born from the same donor's gametes. Kramer posted on a Yahoo message board, thinking if Ryan was curious, maybe other DCs out there were in the same boat. That one message reached quite a few curious people, and began what has grown into the Donor Sibling Registry, with almost 20,000 registered donors, DCs and parents.

Those looking to find a match can register on the DSR's Web site, and search using any available information about their donor (e.g., sperm bank, location, donor identification number). "We're facilitating connections between these people who want to find each other," Kramer said. "It's all mutual consent contact; no one is tracking anyone down, it's only people who want to find each other."

Connecting donors, their offspring and half-siblings is just one part of the DSR's mission, Kramer explained. The organization also seeks to educate its members on issues impacting donor-conceived children, and support the families involved. "We've made basically a community and a place for people to find each other and dialog on these

issues,” Kramer said. “Before we had a central place for these donor families, no one was aware of these issues.”

Just what are the issues? There are a few major concerns for donor families, according to Kramer. “There’s psychological implications of bringing children into the world who will never have the chance of knowing their genetic and ancestral background. There are ethical, social and psychological ramifications here,” she said.

Another issue is the lack of outside governance over sperm banks. Currently, The FDA is the only federal agency charged with overseeing sperm banks, and requires only that they screen donors for various diseases. Other than that, the industry sets its own rules. With no one to answer to, sperm banks could ignore ethical guidelines, like limiting the number of live births per donor in a geographical area. The concern here is inadvertent consanguinity relationships (siblings unknowingly engaging in sexual relations).

One of the main reasons people join the DSR is to share medical information. Recent news reports (see **Sidebar**) have shown the extensive tests donors undergo don’t always catch every medical problem. Knowing genetic history could alert DCs to health risks and allow them to take steps to prevent and detect genetic conditions.

While health history is a major concern, many join the Donor Sibling Registry looking not for genetics, but for family. Profiled in various articles, TV specials and even an “Oprah” episode, many of the registry DCs are trying to fill a void in their lives. Some struggle with their identities, others simply want to meet their fathers and potential half siblings. The success rate is impressive. According to Kramer, between 5,000 and 6,000 people have found each other using the DSR. Hardly a day goes by without at least one match occurring.

### **Open Donor Programs**

The increasing focus on the value of genetics, as well as the fading stigma on infertility, are leading more sperm banks, such as California Cryobank Inc. (CCB), Los Angeles, and Xytex Corp., Augusta, GA, to offer another solution for women looking into sperm donation: open donor programs, whereby the donor agrees to at least one contact with his offspring once the children reach age 18. The contact, which could range from an e-mail to a face-to-face meeting, must be initiated by the child, agreed upon by both parties and is facilitated by CCB for safety purposes. According to CCB, the benefits of using an open donor, which comes at an increased cost, include:

- potential future contact between donor and offspring,
- the opportunity to learn more about the child’s biological heritage,
- donor updates each year for 6 years following participation in the program,
- limited collection and distribution of open donor vials, and
- free registration in the CCB Sibling Registry.

### **DNA Analysis**

For those who have already undergone the insemination process, and donor conceived-children looking for their donors or half-siblings, Kirk Maxey, MD, president, Cayman Chemical, Ann Arbor, MI, a global biomedical research company, has another solution.

Established as part of Cayman Chemical in 2005, the Cayman Biomedical Research Institute (CaBRI), is a non-profit organization working with rare genetic disorders. Dr.

Maxey chairs the Donor Semen Archive, another effort at linking donors and their progeny. Dr. Maxey first became interested in helping donor-conceived children after learning of and registering for the DSR as a donor (he is now a member of the DSR Board of Directors). As he began to read and respond to posts, he realized how powerless some of the DCs and their parents felt. “I gradually became something of an activist,” he said. “I started to think of ways I could help, and DNA sequencing just seemed like the natural, logical answer. It is, in many cases, utterly definitive.”

CaBRI offers both open and confidential DNA analysis for donors and DCs. Donors who wish to remain anonymous can still help their DCs find their half siblings by allowing their genetic information to be added to the database. “CaBRI maintains the highest level of confidentiality and respect for our clients’ need for privacy,” Dr. Maxey said. When matches are made, all parties must consent before results are reported.

Donors joining the project receive their X and Y short tandem repeats (STR markers), as well as their haplogroup. Their X and Y values are entered into the database and, with consent, all parties are notified of any matches. Barring problems with sample integrity, the process typically takes between 4-6 weeks for buccal samples and 5-7 weeks for samples extracted from vials, syringes and straws.

For male DCs, CaBRI analyzes 25 STRs on the Y chromosome. Because the Y-chromosome passes directly from father to son with a high degree of fidelity, it is easy to match male DCs to their donor or to other male half-siblings, Dr. Maxey explained. The organization enters the DC’s Y-STR values in the database and reports identical matches between 25 Y-STR markers, indicating a strong genetic relationship.

Finding matches for female DCs is more difficult, as females inherit two X-chromosomes, one from the father and one from the mother, which rearranges, so an exact copy is not passed from one generation to the next. To determine which X-chromosome was passed along from the father, CaBRI tests the female DC, her biological mother and a close male relative, and compares the X values, which are added to the database.

### **National Donor Registry**

Recently, a few of the major sperm banks are undergoing a philosophy shift and have also begun discussions on creating a national donor registry with patient and donor-conceived children advocacy groups, as well as the American Society of Reproductive Medicine (ASRM), Birmingham, AL.

Sean Tipton, ASRM director of public affairs, told *ADVANCE* while conceptually, a donor registry is a fine idea, in reality, there are many hurdles to overcome.

First, the diverse groups involved need to come to an agreement about what kind of information should be included in the registry, and who has access. More importantly, they need to decide who will be responsible (financially and otherwise) for collecting, maintaining and protecting the privacy of the information. Cost is the biggest hurdle, Tipton noted, especially the cost of maintaining and updating the registry. “We have a very mobile society and it’s hard to keep up with people,” he said.

Realistically, Tipton doesn’t think the perfect solutions to all these questions exist. “It’s unlikely tomorrow there will be a comprehensive donor gamete registry everyone is happy with,” he said. “But I do think that enough of the key players are now actively discussing it that there will be some incremental steps.” Tipton foresees these smaller, but

important steps leading to a less complete registry than is currently envisioned, at least for now. “Learning from those steps might lead to a more comprehensive registry down the line,” he said.

While a perfect solution may not be in the near future, there are important points to remember during the process, Tipton said. “The first and most important thing we want to emphasize is donor gametes are a vital therapeutic option for many patients. So, whatever else you talk about doing, you have to make sure you’re not endangering people’s ability to access that therapy.”

According to Tipton, another integral part of the registry should be maintaining privacy and protecting the information. “It’s very important you not change the rules on people in the middle of the game,” he said. “If people have agreed to donate a gamete or be the recipient of a gamete under conditions of anonymity, those conditions need to be honored.”

Kramer added any effort to create a registry should give a voice to “the people whose very lives are affected by this, the DCs themselves.”

While some donors and recipients will surely embrace a donor registry and look forward to contacting each other, there will not be one answer for every family, Tipton stressed. “If donors and recipients want anonymity, that should be available,” he said. “If donors and recipients want a relationship, that should be available too.” Strong informed consent policies will be vital to helping all parties involved make the decisions that are right for them, he added. “I think the idea there is one solution that applies to everyone is false. We need to help people build their families in the way that works for them.”

*Kerri Penno (kpenno@advanceweb.com) is senior associate editor of ADVANCE.*