

January 11, 2010

## Disclosing the identity of sperm donors

Children conceived from donor sperm during the fertility-industry boom of the 1980s are now becoming adults, and many of them believe they have a basic right to know their genetic heritage. In Canada, as in many other countries, sperm donors are anonymous. But some countries have changed that policy. Debate remains, however, about which rights are more important: the donor's right to privacy or the offspring's right to full identity.

"It comes down to whose interests are going to be privileged," says Juliet Guichon, a medical bioethics professor at the University of Calgary in Alberta.

Austria gives favour to the interests of the offspring, as does Sweden, which banned anonymous sperm donation in 1985. The United Kingdom also has an open registry, though some fertility experts in the country are calling for a return to anonymous donation, which they claim will boost donation levels. That opinion is shared by many fertility doctors in other countries, too.

"Donors should not be forced to release their identity. It should be left as an individual choice for donors to make," Dr. Tamer Said, director of the Andrology Laboratory & Reproductive Tissue Bank at The Toronto Institute for Reproductive Medicine (ReproMed) in Ontario, writes in an email. "Countries that already banned anonymity have experienced a donor semen shortage that is even worse than Canada. In 2009, we received around 600 applications and interviewed almost 20% of them. The overwhelming majority of the donors interviewed indicated that they will not commit into becoming semen donors if their identity is automatically disclosed."

Sperm donors commonly cite a fear of future demands for money from offspring as the reason they wish to remain anonymous. Said says that sperm banks should, however, keep the identities and medical histories of donors on record indefinitely. This information can be consulted in the future in matters relating to an offspring's health.

Some doctors, though, suggest that just because allowing people to donate sperm anonymously increases donation levels doesn't mean it's the right policy. "You are bypassing the ethical argument and going straight to the pragmatic argument," says Dr. Ian Mitchell, a professor of pediatrics and bioethics at the University of Calgary.

Mitchell, along with Guichon, is assisting in the editing of a book on the rights of children of assisted human production. In one chapter, Mitchell wants to tell the story of a medical student sperm donor. Before payment for sperm donations was banned in Canada in 2004, medical students were frequent donors. Thus far, however, he has had no luck finding a former medical student willing to participate. According to Guichon, medical students, and other young men who donated sperm for money, may not have considered the gravity of what they were doing.

"For some reason, people want to pretend that they are not procreating," she says.

Guichon says some children conceived from donor sperm suffer psychological pain because of their ignorance of their genetic, cultural and historical roots.

Furthermore, she says, they have difficulty creating an identity. British Columbia resident Olivia Pratton, who was conceived with donor sperm, is so determined to discover her genetic heritage that she has launched a lawsuit in the BC Supreme Court to allow all offspring over 19 to learn the identities of the donors whose sperm gave them life.

As for the argument that sperm donors were promised anonymity and that the promise shouldn't be broken, Guichon says that offspring were not party to that agreement. These offspring are sometimes told they should be happy just to be alive, says Guichon. "I could be alive because of rape," she says, repeating an argument she has heard donor-conceived people make, "but that doesn't mean I condone rape."

Then there is the fear of genetic diseases being passed on to offspring. In the United States, a sperm donor unknowingly passed on a potentially deadly genetic heart defect to nine of 24 offspring, one of whom died at age two from heart failure. The donor had no symptoms of the disease when he donated sperm, and his family history provided no obvious indication of any danger.

Instead of waging legal battles, some donor-conceived offspring are taking to the Internet to seek out information about their genetic history. For example, Wendy Kramer of Boulder, Colorado, who has a son through donated sperm, started an online registry to help connect sperm donors with offspring. So far, the Donor Sibling Registry has attracted more than 25 000 members from all around the world and has facilitated 7000 matches.

In the future, suggests Guichon, society may become more supportive of donor-conceived children seeking out the identities of donors. "There is social approval of adopted children looking for their parents," says Guichon. "Why facilitate reunions in one group and not the other?" — Roger Collier, *CMAJ*

DOI:10.1503/cmaj.109-3144