

The 2005 international symposium on

THE FUTURE OF DONOR CONCEPTION

Toronto, Canada. October 22-23, 2005

Sponsored by the Infertility Network, www.InfertilityNetwork.org

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NB. A video of the presentations and books by many of the speakers are available from the Infertility Network. Please see the bottom of this report, and the enclosed ORDER FORM, for details.

In October 2005, the Infertility Network hosted an international symposium on donor conception. Speakers included donor-conceived adults, parents via sperm and egg donation, mental health clinicians, representatives of sperm banks, authors, ethicists, government officials and academics. Topics ranged from single parenthood to embryo adoption and were addressed in terms of policy, legislation, research and education. Although the speakers represented a wide range of perspectives, there was a general consensus that reproductive medicine must focus primarily on the best interests of offspring, instead of – as it has to date – on the perceived needs of infertile couples. In a lively, respectful dialogue that often included several points of views, speakers addressed the following:

1. **The significance of genetic connections.**
2. **Ways in which the practice of donor conception should change so that it can serve the best interests of the children**
3. **The changing nature of kinship and family**
4. **The power of language**

This paper attempts to summarize conference participants' perspectives on each of the central themes of the conference.

THE SIGNIFICANCE OF GENETIC CONNECTIONS

The significance of genetic connections was addressed most articulately by donor offspring who spoke poignantly about what it means to live with "fractured kinship." They acknowledged that there are others – e.g. adoptees, victims of natural disasters, etc. – who lose contact with genetic relatives. However, none could think of an instance, other than donor conception, in which there is the *intentional* disruption of genetic ties. Furthermore, speakers noted the double standard that prevails in reproductive medicine whereby every effort is made to preserve genetic continuity for would-be parents, but little, if any, effort is

made to preserve genetic continuity for their donor-conceived offspring.

Both offspring and donors spoke about the desire to know people to whom they are connected genetically. Neither group seeks to replace the parents or children they have, but rather, to know others with whom they share a genetic heritage. Two young women, Rebecca Hamilton² and Jo Rose³, exquisitely conveyed this need.

Rebecca discussed her search for her biological father. Born at a time before records of donors were kept in New Zealand, she talked about how frustrating it is when there is no system to help donor-conceived people navigate the difficulties involved in searching. Rebecca ultimately made a documentary about her attempt to find her biological father. The film was broadcast on national television in New Zealand and was a catalyst for the legislative changes that have since taken place there.

In this vein, Rebecca was heavily involved in the development of the New Zealand Human Assisted Reproductive Technology bill, which became law in 2005. The law mandates that identifying information about the biological parents of donor-conceived children is kept at a central register and made available to them upon adulthood, thus ensuring that no person will be put in her situation of 'genealogical bewilderment' in the future. The legislation also includes a provision to enable donors, and offspring who were born before the legislation was enacted, to register their details and make contact with each other if they wish. (Rebecca is currently pursuing a joint degree as a Harvard University Knox Fellow; in 2007, she will graduate with a law degree from Harvard Law School and a Master of Public Policy from the John F. Kennedy School of Government.)

Jo Rose took the issue of offspring rights and identities to the High Court in the United Kingdom (UK) where she was born. The ruling of the court that "an AID [artificial insemination by donor] child is entitled to establish a picture of his/her identity as much as anyone else" added to the pressures on the UK government from other sources and helped lead to the April 2005 ban on donor anonymity, and to the establishment of a retrospective gene library to aid donors and offspring in establishing voluntary contact with each other. (Jo did her Honors BA on the ethics of donor conception, interviewing donor offspring, and is now in the latter part of a PhD looking at the ethics, philosophy and sociology of donor insemination (DI). She is a member of Tangled Webs, www.tangledwebs.org.au, an international organization which opposes donor conception due to the intentional fracturing of genetic kinship that it entails.)

Speaking eloquently, Rebecca and Jo zeroed in on several critical issues in DI which include:

1. Even when DI parents "do everything right" as some of their parents did, offspring can still experience a profound sense of loss and disconnection.
2. It is insulting to say to offspring, "Would you rather not have been born?" No one asks this question of others who are suffering, such as those who live with a chronic disability or face a grave illness. Speakers emphasized that even people experiencing great physical and emotional pain rarely, if ever, regret being born. Donor offspring identify this as "existential debt" – they are supposed to be eternally grateful for being born and to ignore, or "get over," the circumstances of their conception.
3. There exists a "double standard" with regard to adoptees and offspring. Today, few people would say to an adoptee, "You are lucky you were so wanted" because the loss in adoption is now recognized and respected, as is the desire for reunion on the part of many birth parents and adoptees. However, some people will say this to offspring, thereby negating the loss that many of them feel. To the comment, "You were so wanted," offspring say, "So what?"
4. Offspring object to being labelled "unstable" or "unbalanced" or "using it a crutch" when they express the loss they feel. They note that their pain is so often disenfranchised, while the pain of other groups, especially the infertile, is more readily acknowledged and responded to with compassion.

5. Offspring remind us that none of us are "frozen in time." Donors may have accepted or even wanted anonymity years ago, but may now be quite willing, even eager, for contact, as evidenced by the donors who come forward after stories appear in the media.
6. The only thing some offspring know about their genetic fathers is that they masturbated into a cup. Some are deeply troubled by the fact that their genetic fathers were so willing to permanently transfer their parental rights this way.
7. Above and beyond all else, offspring emphasize that they have as much of a right as everyone else to have a clear picture of their identities, in addition to full access to complete and regularly-updated family medical history, for purposes of identity formation and in order to protect their own health as well as that of the children they have, or will likely one day have.

WAYS IN WHICH THE PRACTICE OF GAMETE DONATION CAN BE MODIFIED TO SERVE THE BEST INTERESTS OF THE CHILDREN

This conference heard from several offspring who believe that all gamete donation should end because the intentional fracturing of kinship can never be aligned with the best interests of children. Other participants, including donors, parents, professionals and other offspring, felt that gamete donation can continue as long as it is practiced with full openness and without payment to donors (other than perhaps reimbursement for expenses directly related to the act of donation).

1) End Anonymity

Included among the speakers was a researcher from The Sperm Bank of California (TSBC), Dr. Joanna Scheib, who described their pioneering work with "identity release" donors (men who have agreed to be identified and available to offspring when the children reach age 18). Since 2001, the first year that identity release TSBC offspring came of age, there have been approximately 25 adolescents interested in finding their genetic heritage. An equal distribution of boys and girls have come forward, some seeking meetings and others simply wanting information. Most of the offspring report positive feelings about having been told of their donor conception, saying such things as "It's all I know" or "It's not such a big deal." Their feelings towards their donors are ones of curiosity and excitement. Some want to meet the donors and those who do, anticipate experiences ranging from a one-time meeting, to a "friendship," to a relationship with the donor that was akin to an "uncle." Nearly all

the donors have stood by their original decision to be identified; they report feelings of curiosity, interest and caring. Most had told someone they had donated.

2) Let The Truth Be Told

Everyone attending this conference was aware that there are parents, and even professionals, who believe in lying to children about how they came to join their families. No one at the conference condoned this practice. Rather, several presentations focused on the importance of truth telling and one, in particular, addressed questions of how and when to talk with children.

Olivia Montuschi², co-founder of the Donor Conception Network (DCN)⁴ in the UK, and mother of two young adults conceived by DI, offered guidance about talking with children from a developmental perspective. The DCN encourages parents to begin talking openly and honestly to their children as infants, so that they get used to the language and to telling a happy story, and the children grow up with the information about their conception integrated into their self-concept.

Olivia stressed using simple language, which young children can understand, and accompanying this with pregnancy and baby pictures. For children 7-11, she reminded people that children in this age group are often not all that interested in the donor story. She encourages parents to put their own “baggage” aside and to listen to what concerns their children; she emphasized that what matters most to children during this time is feeling loved and secure. She sees the 7-11 period as one of “continuing the conversation”, one that – hopefully – began years earlier. Olivia noted that waiting until adolescence to tell is hazardous because this is a particularly difficult time when teens are already “pushing against their parents”. She recommends parents draw secure boundaries when teenagers say things like “You are not my real...” and suggests such responses as, “Well I’m the one you have and always will be.”

3) Put The Best Interests Of Children First

To offspring, it often seems that the infertile couple takes centre stage, with their children expected to understand kinship in terms of their parents’ infertility. The pain of the children is seen in the context of the pain and losses of the parents. Moreover, the parents’ losses are seen as “objective” because infertility is more likely to be understood and acknowledged. By contrast, the losses experienced by offspring are considered

“subjective” — physicians, mental health professionals, parents and society in general too often fail to comprehend “what we are so upset about.”

Offspring repeatedly emphasize the fact that they are not comforted by being told they were “loved and wanted.” They object to the notion that parental love trumps the right to one’s whole identity and their access to family medical history.

4) End the “Medicalization” of Gametes

Offspring and other speakers commented on how strange it is that eggs and sperm – the “seeds of life” – are often “medicalized” by physicians and others in the field. One practitioner was even quoted as referring to “doses” of sperm. The head of a patient support organization was quoted in the national media as calling sperm “just spit” (www.montrealmirror.com/2005/092205/news1.html) Conference participants were baffled by the fact that physicians call egg and sperm donation “valid medical treatments,” thereby diminishing the role of the donors as genetic *parents*, and making eggs and sperm seem like medical *products*, no different from the latest blood pressure medication or cholesterol lowering drug. Some offspring were profoundly troubled by the fact that, in most instances, the two people who gave them life had never even spoken to each other, despite the fact that each had implicitly agreed that they would create new life together. Grandparents, aunts, uncles, cousins and, of course, siblings, also lose out from this intentional fracturing of genetics ties.

5) Limit/Abolish Payment

Conference participants came from around the world and hence, had very different experiences regarding payment for donor gametes, especially with regards to ovum donation. Some were from countries where no payment is permitted (now including all European Union countries) or where there is reimbursement for expenses (Canada, Australia). Others, from the USA, live in a society where women routinely receive large payments for egg “donation.”

While participants had different perspectives on whether *any* payment should be permitted, all agreed that every effort must be made to avoid the commodification of human gametes. It is hard enough to grapple with fractured kinship; learning one was the product of a financial transaction can prompt feelings of shame and disgust, make offspring feel like a “commodity,” even, as some said, create a real “yuk” factor.

THE CHANGING NATURE OF KINSHIP

Single^{1, 5} and lesbian mothers spoke of their experiences “redefining family.” Respectful of the feelings and perspectives of offspring, they related their own deep desire to create families for themselves without men, either because they were in lesbian relationships or because, as single heterosexual women, they were concerned about their “biological clocks” running out and chose single motherhood “by default” rather than risk childlessness. Either way, their paths to parenthood involved donor sperm from friends, or from known or anonymous donors. Concerned about the perils of anonymity, lesbian women sometimes create “different forms of families” such as two lesbians and a gay man/couple coming together to create children who will grow up with full knowledge of, and connection to, their genetic families.

Although some participants oppose all gamete donation, others struggle to find ways to “make it OK.” These include bringing the donors into their children’s lives, talking openly and continuously with children about what it means to them to be donor-conceived, and wanting to see two types birth records established for *all* children, not just those born through gamete donation — a valid, authentic “birth certificate” that lists the genetic parents, and a “legal parentage certificate” which gives the names of the rearing parents and can be used for school registration, sports enrollments, medical care, etc.

THE POWER OF LANGUAGE

Words really affect how we think about something. Should someone be called a “donor” if they receive payment, or is this just a euphemism, designed to gloss over what is really going on (cash in exchange for sperm/eggs) and make everyone – patients, gamete providers, offspring, physicians, elected representatives, society as a whole – feel more comfortable, and less critical of gamete donation as a practice? How does someone feel about taking the last name of their rearing father when their genetic father has another name? How can a physician refer to donor conception as a “treatment?” when it does nothing to fix whatever caused the infertility but instead, like adoption, is another route to parenthood? Why do people use the word “disclosure” in referring to donor conception – doesn’t “disclosure” connote secrecy and shame? Is an embryo a “little person” or “just some frozen cells?” Should embryos be “donated” or given the protections inherent in adoption (a homestudy, legal arrangements, etc.)? These are but a few examples of how questions regarding language played a central role throughout the conference.

Participants agreed that reducing some of the misuse of language would contribute to real change in the practice of gamete donation. For example, if the word “vendor” replaced “donor” in instances of paid donation, both donors and recipients (who are, in reality, sellers and buyers) might be prompted to look more carefully at what they are doing, reconsider whether this is really an “altruistic act” (as physicians and others like to identify it) and might challenge their feelings about whether, or not, payment or even gamete donation itself, is an acceptable practice.

MOVING FORWARD

Although sorrow and anger were a significant part of this two-day conference, they were accompanied by optimism and determination. Participants, though outraged by many aspects of the current practice of donor conception, are hopeful that change is underway.

Near the close of the conference, Eric Blyth⁶, a Professor of Social Work in the UK, as well as an internationally recognized researcher, author and policy consultant to governments, professional and patient organizations on the psychosocial aspects of donor conception, reminded everyone there that it was not so long ago that secrecy prevailed in donor conception, with parents instructed by medical professionals not to tell the truth to their children. Although there is a long, long way to go, and some very troubling practices are gaining momentum (e.g. fertility tourism, embryo donation), much has happened in recent years that offers cause for hope. In particular, people can appreciate and celebrate the end to anonymity in a growing number of countries (the UK, the Netherlands, Sweden, Norway, Iceland, Finland, Switzerland, Austria, New Zealand, and the states of Victoria and Western Australia) and the directive from the European Union banning all payment for gametes in EU member nations.

Several times during the conference, people commented on how most of the donor-conceived participants were crying. Indeed, there were times when their sadness seemed to permeate the room. However, this conference, like the ones that have preceded it, also organized by the Infertility Network (in 1997, 1999, 2000, 2002), have served to give this once disenfranchised group a voice. Offspring spoke loudly, with confidence, clarity, vision and determination. And instead of being few in number, there was a large international group of them in attendance to offer support to each other. Perhaps some of their tears were tears of gratitude, that at long last they are beginning to be heard.

**The following books & videos are available through the Infertility Network.
Please see the enclosed ORDER FORM.**

SYMPOSIUM VIDEO

The Future of Donor Conception: Where Do We Go From Here?

Single mothers by choice: Mikki Morrissette^{2, 5}, (USA), Author, *Choosing Single Motherhood – The Thinking Woman's Guide*

Lesbian, gay, bisexual, trans, queer parenting: Rachel Epstein, (Canada) LGBT Parenting Network,

Having your baby using egg donation: Ellen Glazer (USA), Social worker specializing in reproductive medicine & adoption. Parent through birth & adoption after infertility & miscarriage. Author of *Having Your Baby Through Egg Donation*.

All in One Basket: a documentary on egg donation by Lauren Berliner

Should ethics & money mix in donor conception & surrogate motherhood? Phyllis Creighton, Historian. Ethicist. Member, *Health Canada Advisory Committee on Reproductive & Genetic Technologies*.

The Assisted Human Reproduction (AHR) Act: Francine Manseau, *Health Canada*

Finding your genetic family (half-siblings & donors): Wendy Kramer & Ryan², her son via DI. Co-founders of the *Donor Sibling Registry*. (USA)

How to tell children about their donor conception: Olivia Montuschi², *Donor Conception Network*. (UK)

Open-identity sperm donors & donor-conceived adolescents: Joanna Scheib, *The Sperm Bank of California*.

Panel discussion:

- Jane French (Canada), Mother via egg donation
- Eric Schwartzman (USA)², Father of 2 via DI
- Mark Lyndon (UK), Former sperm donor
- John Sylla (USA), Former sperm donor

The mediation of kinship & identity: Jo Rose, Donor Offspring (Australia & the UK)

Comparing Policy Cultures – UK vs Canada: Mavis Jones, Sr Research Associate & PhD candidate (UK)

Embryo adoption: Megan Corcoran, *Snowflakes Embryo Adoption Program* (USA)

Understanding what it means to be a donor offspring: Parrish Protheroe, PhD (USA)

The struggle for dignity in donor conception: Bill Cordray (USA). Donor Offspring. Advocate for reform.

Meeting the challenges posed by the abolition of donor anonymity: Eric Blyth, Professor of Social Work (UK)

Panel discussion:

- Shirley Pratten (Canada), *New Reproductive Alternatives Society*
- Olivia Pratten, Shirley's 23 year old daughter via DI
- Lindsay Greenawalt (USA), Donor Offspring
- Lynne Spencer (USA), Donor Offspring

BOOKS BY SPEAKERS

¹ **Having Your Baby Through Egg Donation** By Ellen Glazer.

Compassionate support & essential information on the medical, ethical & psychological aspects to help married, single or lesbian women & their partners, as well as gay men/couples, decide whether egg donation is right for them, using an anonymous or known donor.

² **Behind Closed Doors: Moving Beyond Secrecy & Shame** includes essays by several speakers: Rebecca Hamilton, Mikki Morrissette, Wendy & Ryan Kramer, Eric Schwartzman, Olivia Montuschi, plus a formerly anonymous donor & another donor offspring.

³ **Who Am I? Experiences of Donor Conception** includes an essay by Jo Rose, along with essays by other offspring, plus reflections by Dr. Alexina McWhinnie, a social researcher.

⁴ By the Donor Conception Network:

Books

- **My Story / Our Story** (Separate versions for children from various types of families – egg donation; single mothers; heterosexual or lesbian couples)
- **Choosing to be Open about Donor Conception: The Experiences of Parents**
- **Telling & Talking About Donor Conception: A Guide for Parents** (Separate versions for parents of children aged 0-7, 8-11, 12-16, & 17+ years old)

Videos

- **A Different Story** – Varied, positive, thoughtful reflections by DI offspring, aged 7-20.
- **Telling & Talking About Donor Conception** – Parents & children in 10 families created through egg, & sperm donation.

⁵ **Choosing Single Motherhood: The Thinking Woman's Guide** By Mikki Morrissette Based on extensive up-to-date research, advice from child experts & family therapists, & conversations with more than 100 single women & their children..

⁶ **Third Party Assisted Conception Across Cultures: Social, Legal & Ethical Perspectives** Co-edited by Eric Blyth. Essays by donor offspring, egg donors, a DI mother, a mother through surrogacy, a family through adoption, as well as counsellors, researchers & lawyers.

Truth & the Child 10 Years On: Information Exchange in Donor Assisted Conception Co-edited by Eric Blyth. Essays by donor offspring, egg donors, a DI mother, a mother through surrogacy, a family through adoption, as well as counsellors, researchers & lawyers.